

Modernising Wheelchair & Seating Services in Scotland: An Action Plan

Thank you for giving Quarriers the opportunity to respond to this consultation. Quarriers is a Scottish-based charity providing practical care and support for children and adults with disabilities, children and families, homeless young people, people with epilepsy, and carers. Through more than 120 projects in Scotland and south west England, we challenge inequality of opportunity and choice, to bring about positive change in people's lives.

This consultation has been considered by practitioners working to support adults and children with disabilities, as well as many of the people we support who use wheelchairs, and our response reflects these discussions.

We welcome the publication of the Draft Action Plan, as a long-awaited and much-needed step forward in improving the Wheelchair and Seating Service (WSS) in Scotland. We also welcome the additional funding provided by the Scottish Government, although it is disappointing that, at £16m spread over 3 years, this is around half the estimated costs of implementing the recommendations of Moving Forward.

Overall, however, we are concerned that this Draft Action Plan is focused on the medical model of health service provision, failing to see people who use wheelchairs as people with aspirations and potential for achievement that go beyond patients with medical and postural needs. Much of the content and tone of the document reflects this approach and concentrates on making adjustments to existing provision, rather than adopting a social model of disability which concentrates on maximising and supporting a person's ability to reach their full potential by using a person-centred approach. A key example of this is the retention of eligibility criteria until at least 2010, which may permit the WSS to meet budgetary requirements but leaves many of the most vulnerable people in our communities excluded from accessing the equipment they require. The Action Plan as it stands is a missed opportunity to introduce the more fundamental changes required to develop a responsive service which takes a broader, holistic, view of service provision, recognising the interface between social and health needs and the desirability of self-assessment and self-management wherever possible.

We are also disappointed that the basic structure of the WSS remains virtually unchanged, despite the recommendation in Moving Forward that a single, national structure should be established. A national body would have had the ability to oversee provision and ensure consistency across Scotland, but may also have provided an opportunity to introduce the cultural and attitudinal changes in perceptions and values required.

Patient and user involvement

This must be an actively participative process which includes people with multiple and complex disabilities, (including people with learning difficulties and limited verbal communication), carers and providers. Adequate resources need to be allocated to support this activity, and arrangements made that recognise the many and diverse commitments of people who use wheelchairs.

Consideration should be given to the use of existing forums of people who use wheelchairs, including less formal clubs as well as recognised organisations, and facilities for people who use wheelchairs such as disability resource centres

For many people, it seems that small concerns about minor issues are ignored and allowed to escalate to major problems. A process where people could provide feedback, both positive and negative, on their experiences, without having to resort to the formal complaints procedure would be welcomed.

In addition, better use could be made of a range of customer satisfaction survey mechanisms, particularly if this was undertaken on a long-term basis to show developing trends. Feedback to participants on what happens to the information they provide would be an important part of this.

Partnerships and collaborations

We would support closer links being made with social care providers, particularly those in the voluntary sector, to ensure that the needs of the people we support are better understood and are at the centre of “case management”. This is especially important if an anticipatory approach is to be adopted. There are too many instances where the views of support workers and family members are disregarded, and where they are perceived as irritating and even antagonistic, because they are unwilling to accept a service they deem to be unacceptable in meeting the needs of the person they support. This provides a welcome opportunity to establish more positive working relationships between the voluntary sector providers and health professionals in the WSS.

In addition, it is important that collaboration between different parts of the health service are improved, to ensure that people who use wheelchairs are not passed from one section or department to another. It is not unusual for people who use wheelchairs to become embroiled in disagreements involving OT, social work, physiotherapy and WSS, none of which provides the “seamless journey through the pathway of care” which should be the norm.

Service redesign

The national Referral to Treatment Target is set at 18 weeks for the entire patient journey. For a person who requires a wheelchair for much or all of their daily life, this would be an unacceptably long period of time to wait. It is unreasonable to suggest that a person should have to stay at home, possibly in bed, for 18 weeks and emphasises the lack of understanding of the importance of a wheelchair as an essential facilitator for lifestyle choices for many people.

Building capacity

The establishment of local clinics to provide straightforward wheelchair requests would be useful and should have a range of different services including assessment, provision of standard equipment and, at the very least, minor repairs such as replacement lap belts or footrests. These local clinics should be multi-disciplinary, with a systematic approach to identifying and providing the various aids that a person might need, instead of a person having to trail around many different clinics. It would also be helpful if local clinics were able to provide an out-of-hours service. A local clinic dealing with straightforward cases would reduce delays for everyone, maximise efficiency and make it easier for more complex needs to be addressed.

Referral, assessment and provision

Referral

Existing wheelchair users can currently self-refer directly to the WSS centres for review and re-assessment. However, this is not widely known, and needs to be better publicised. Having to wait for a “professional” referral only adds to the waiting time for assessment, which can be lengthy with delays of up to 6 months common.

Assessment

Assessments should be “whole-life” and need to include social needs and carer requirements as well as mobility needs. An assessment made on purely medical grounds, which takes no account of a person’s lifestyle, social activities and aspirations, is not meeting the needs of the wheelchair user. There needs to be greater recognition of the inter-dependency of health and social requirements, which would flow naturally from a person-centred approach to provision, and would see the individual as an equal partner in achieving their full potential, rather as the recipient of a medical aid.

Greater consideration needs to be given to including people with communication difficulties and multiple and complex needs. This might include better use of information already held by support workers, carers and family members, which relates to the practical aspects of an individual’s lifestyle and how the wheelchair enables or prevents maximisation of social inclusion.

Carers’ assessments need to be an integral part of this process to ensure that issues that impact not only on their ability to care but also on their own lives, including their health, are identified and addressed.

In addition, as a responsible employer, we have a duty of care to our employees, and if an assessment takes no account of a carer’s ability to push an individual who is unable to self-propel their chair, (whether that be a paid or unpaid carer) then it may compromise the health and safety of that carer.

Provision

NHS wheelchair services should be based on the principle of universal provision of a wheelchair to meet not only mobility needs but also social needs and carer needs.

Current eligibility criteria for powered wheelchairs excludes many people with learning and physical disabilities, and some sensory impairments. This inequality of access to resources prevents people with profound and complex needs from accessing the equipment required to achieve their full potential. Using eligibility criteria in this way to ration access to resources is unreasonable and unjust. This is a major omission from the Action Plan and proposals to develop new national eligibility criteria by October 2010 are unacceptable. We would ask that this use of eligibility criteria to mask inadequacies in funding be removed immediately. Regardless of budgetary constraints, the fact remains that some of the most vulnerable people in Scotland are being penalised. Whatever the cost savings of this decision have been, the price paid by some of the most disadvantaged people is too high.

Equipment, repairs and maintenance

Upgrading of the wheelchair fleet with new equipment must include attendant-controlled powered wheelchairs. It makes no sense for technological advances which can vastly improve quality of life for many to be ignored purely on the grounds of cost.

There also appear to be serious design flaws on some of the most basic elements in many wheelchairs, eg brakes and wheels, and correction of these defects prior to issue would eradicate much of the needless time, expense and distress expended in correction.

A key omission from the Action Plan is the development of agreed response times for repair and maintenance. This leaves many people who use wheelchairs with no idea when their wheelchair will be returned so that they may continue with their normal daily lives. It also makes it extremely difficult for support service providers to plan staff cover and arrange community activities.

In addition, an out-of-hours service should be introduced, not just explored as a possibility. And a mobile repair service would be a welcome development for most people who use wheelchairs, particularly those in rural and remote areas.

Regular maintenance of wheelchairs may prevent more serious problems arising and thus save time and unnecessary distress for the individual, as well as reducing WSS costs. The introduction of this provision is welcomed.

I hope that the above is helpful but would be happy to provide further information if that were useful and to discuss further the work of Quarriers and the people we support.

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