

## PAMIS Consultation Response *Wheelchair and Seating Services Modernisation: Draft Action Plan*

PAMIS is a registered charity based in Scotland. We work in partnership with families caring for a relative with profound and multiple learning disabilities (PMLD) and complex health needs. PAMIS provides a range of services for families, including individual support, information, training and opportunities to influence policy and services. We welcome the opportunity to respond to the Draft Action Plan.

Almost all children and adults with PMLD are completely dependent on a wheelchair, not only for mobility but also for postural support. Few if any can self-propel and are dependent on their carers to push their wheelchairs. A person-centred multi-disciplinary approach to their wheelchair and seating needs is therefore essential to health and wellbeing. The carer's needs must be taken into account; most carers of people with PMLD have musculo-skeletal problems, related to moving and handling a very dependent relative over long periods of time. Obviously providing a wheelchair which minimises the pressure on carers' physical wellbeing is a crucial investment in a carer's health and ability to carry on caring.

This response draws on: PAMIS' experience of working with families and relevant professionals over the last 15 years; a group discussion between families known to PAMIS who live in South Lanarkshire; other comments on the Draft Action Plan made by individual families; and also by the PAMIS Events and Promotions Officer, who herself has very complex health needs and is dependent on a wheelchair. In addition, PAMIS has taken into account comments made by users, carers and service staff made at the recent consultation event the agency organised in Aberdeen.

### **General comments**

The Draft Action Plan sets out a much-needed programme, following on from *Moving Forward: Review of NHS Wheelchair and Seating Services (March 2006)*. The additional £16 million for the services allocated by the Scottish Government for the period 2008-2011 is of course also very welcome, but is much less than the target budget identified by *Moving Forward* of £30 million per annum after 3 years. This means that there is a continuing need to raise political awareness of current wheelchair issues.

The Plan therefore has to be seen in the context of making hard decisions about allocating the funds currently available. We are grateful to Ian Hood of the Learning Disability Alliance who has written a comparison of the Plan with *Moving Forward*, identifying what has been included and what omitted.

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## **General Comments**

A National WSS Service: *Moving Forward* envisaged the creation of a national, integrated wheelchair service, which could deliver a consistent service and avoid the current experience voiced by users and carers of a 'postcode' lottery. Shared resources, information and expertise would be part of this picture. The main emphasis of the Plan seems to be about developing regional structures and processes. These are designed to underline the responsibility of each NHS Board for wheelchair provision and for engaging with users and carers through Public Partnership Forums.

PAMIS strongly supports this emphasis on greater accountability by individual Boards. There is however a continuing need for national co-ordination, pooled resources and information, equity and monitoring of the service. A central body to run the service had not been put in place.

A person-centred whole life approach: In our view, while the Plan that indicates an intention to establish this approach to wheelchair provision, the Action Points do not give sufficiently robust and practical detail to be effective. The Plan appears to be still based largely on a medical model and this is particularly true of the section on partnership working and assessment.

PAMIS strongly supports the Plan's emphasis on establishing a local clinic system. This is an opportunity, not only to be more accessible to users and carers, but also to develop a much more person-centred approach, and a 'one-stop-shop' structure. Thorough and inclusive assessment is the foundation of a good service and must take **all** aspects of a person's life into account. Careful attention needs to be given to co-ordinating the process involved – including review – and involving all the people who should contribute, including user, carer and non-medical service staff involved in all aspects of their daily support for mobility.

Carers' needs: The relevant Action Point in the *Referral Assessment and Provision* section relies too heavily on the existing Carer Assessment mechanism linked to Single Shared Assessment. In our experience, carers and carer agencies share a widespread distrust of the Carer Assessment. Carers' entitlement is limited to the right to be assessed, not the right to any action. The assessment would not be sufficiently detailed or robust to take wheelchair management by carers into account. PAMIS would want to see a specific and practical carer assessment built into the wheelchair assessment process, looking at carer health and capacity and training and support needs. This could be done with local authority and voluntary sector partners.

Private purchase: It is disappointing to see that advice and technical support to families purchasing privately has been omitted from the Plan. Top-up arrangements have also not been included.

Ongoing communications and further consultation: The consultation events organised by the voluntary sector on behalf of the Scottish Government have been welcomed by all. We see this as the start of an ongoing consultation on a wide basis. A variety of ways of connecting users and carers from all over Scotland to the work of the Project Board and a two-way communication process need to be developed.

## Detailed comments

### Patient and User Involvement

The emphasis on user and carer involvement is very welcome. It needs to apply to all tiers of the system - i.e. WSS Centre, NHS Board, National Procurement and WSS Project Board. The overall balance of the Project Board should be reconsidered. There needs to be a spread of representation of users and carers in all such groups, with differing requirements, ages etc, and also, at national level, from different areas of Scotland. This should be supported with the right resources for example to allow for the need for personal carers and travel. Proactive measures to include users and carers should be taken by NHS Boards and WSS services by contacting user and carer agencies.

In order to contribute to decision-making, users and carers must be given good information and communication systems. A bulletin board for the WSS Project Board and the WSS services could be set up but not relied on exclusively. Non-electronic means of communication are also very important especially to some older people.

### **Partnerships and Collaborations**

The recommendation that each NHS Board has professional leadership is strongly supported.

The emphasis on partnership and MDT working is also welcomed, and inclusion of WSS within the Rehabilitation structure. This does however appear to be thought of largely along medical model lines. Partnerships with service providers supporting **all aspects of a person's life** should be set up – e.g. travel. Schools, work, housing etc. Transitions are key times for partnership.

PAMIS would like to know more about the role of the Rehabilitation co-ordinator. We would like to see practical rehabilitation or mobility co-ordinator posts, to act as a key link with WSS for users and carers. Their role would be to ensure a whole life approach to wheelchair provision. He/she would liaise with users and carers, consult with medical professionals and with the relevant community services and arrange 'one-stop-shop' assessments.

Such a person could work to ensure that the rather abstract aspiration that *“wheelchair users and their carers should experience a seamless journey through the pathway of care that ensures they receive the right intervention at the right time”* became more of a practical reality.

### **Service Redesign**

Inclusion of wheelchair provision in the RTT target is welcomed, although families were disappointed that the target date was not until 2011. However, a priority system based on levels of dependence on a wheelchair and medical need must be developed to reduce waiting times to a minimum in urgent situations.

## **Building Capacity**

### *Local Clinics*

The idea of local clinics and more staff was welcomed by families. The suggestion of travelling clinics similar to breast screening clinics was made. Families felt it particularly useful to handle wheelchairs rather than to see them in a brochure and thought that this service combined with the chance to speak to professionals would be of great benefit particularly in rural areas.

Local clinics should be run on a 'one-stop-shop' multi-agency, MDT basis.

Transport arrangements and the number of clinics would both affect the improvements brought.

Transport to clinics must make provision for users who are dependent on a personal carer to travel with them. In some areas, WSS transport providers will not accommodate carers. This has the effect of penalising those with the most complex needs by forcing them to take a taxi. This is completely unacceptable.

### *p.13 Supporting Definitions*

Families wanted all 3 tiers, simple cases to complex cases, supported locally.

*p.13 para 3* "It is particularly important that services are delivered in a timely way as delays to provision for children can have disproportionate effect" was strongly agreed with.

## **Referral, Assessment and Provision**

### *Referral*

It is very positive that a variety of registered healthcare professionals will be able to make referrals. New information leaflets will be needed to publicise this right. Self-referral for existing users and carers is also a very positive move.

### *Assessment*

Both the PAMIS families group and the discussion groups at the Aberdeenshire consultation event thought that the "standard assessment tool" should be designed by users, carers and professionals to ensure a holistic assessment. The Aberdeen groups specified that:

- Carer and user perspective should be part of MDT designing SA.
- It must include risk assessment, environment, carer/user perspective etc. Descriptive assessment, not yes/no questionnaires.
- It must be benchmark – as good as it can be at beginning of process. Must include guidance on what to do if things go wrong.

The Aberdeen groups also made the following specification:

The assessment must be holistic and cover/include:

- lifestyle, environment, clothing worn, multi-use of chair, user's means of communication, transition from primary environment to secondary where power chair may be needed. Whole life needs to be assessed - person

involved in sport assessed differently by one who uses chair to get from A to B.

- User's other needs – e.g. sight or hearing problems, literacy skills, level of understanding, English not as first language etc.
- Carer's needs and family. Carer's environment to be assessed and its impact on ability to care.
- Carer and user expertise – must be listened to (staff training implications)
- Need of carer and user for information/training in use of wheelchair
- Children – environment and transport assessment especially important, because of number of environments they use and of their activities.
- Transport – any additional equipment be needed (if so who provides? Better if all as a single package)
- Body brace requirement
- Follow-up assessment after provision – 3-4 weeks later to fine tune.
- Reassessment - especially after adjustments. Onus currently on service user to ask for this – onus should be on services instead. New IT system should organise reviews.
- Formal review process– at least annually. May just be a phone call for some. To take into account changes in body shape etc. One person not seen at all by WSS from ages of 13-26 – considerable growth and shape change in meantime.
- A delegate from Orkney suggested use of Telemedicine for island communities with complex cases e.g. Multiple Sclerosis and Motor Neurone Disease who need frequent reviews on 'as and when' required basis, as next time clinic is held may be on to another stage of condition.
- Annual servicing of chair – dates to be built in to assessment
- Level of dependency on wheelchair – affects prioritisation of provision and repair time
- Level of support at home e.g. if person lives alone – affects prioritisation of provision and repair time
- Repairs:
  - minor ones to local bike shop/ private companies? Chair a lifeline, not just piece of equipment.
  - Out-of-hours service – criteria for this should be built into initial assessment. Tiered system of criteria.
  - Time-scale for repairs and criteria for urgency
  - Knowledge of end-products will contribute
- Need for temporary replacement wheelchair

### *Provision*

Equipment **must** be suitable for carers as well as users and families wanted greater publicity and attention given to national eligibility criteria.

Current eligibility criteria for powered wheelchairs exclude 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 receiving the equipment the need to achieve their full potential.

Equally seriously, it also means that carers who badly need power assistance to be able to push a wheelchair do not receive it. Many unpaid family carers of people with long-term conditions such as PMLD suffer severe musculo-skeletal damage as a result. This situation becomes very much worse as they become older and the person they care for becomes adult or as their condition progresses.

Eligibility criteria are thus being used to ration access to resources for some of the most disabled people in Scotland and their families. This is unreasonable and a major omission from the Action Plan. The proposal to develop new national eligibility criteria by October 2010 will leave these families in this position for at least another two years.

The failure to support carers and to protect their health in this way is not only unsupportive of their needs and wellbeing, but is also a very false economy, given the many millions of pounds carers save the NHS and local authorities each year by preventing the need for long-term care.

### *Delivery*

A maximum timescale that you should have to wait for your wheelchair was wanted. This would possibly need to be tiered i.e. simple case -1 month, complex case – 3 months. It was suggested that an Occupational Therapist and technician deliver the chair to ensure it works as according to the assessment. There should be a follow up too after several weeks of having the chair to check that it is suitable for the user's/carer's needs.

## **Equipment, Repairs and Maintenance**

### *Equipment*

Upgrading of the wheelchair fleet should include investment in carer propelled powered chairs (see above). Light-weight materials will also benefit carers.

The range of equipment currently available is seen as restrictive by families of both adults and children. A database used/outgrown equipment would be valuable.

Information on what is available is needed.

### *Repair and Maintenance*

Annual MOT's were suggested for more complex wheelchairs. It would be helpful to have "multiskilled" technicians rather than people focusing on a particular part i.e. someone delivering wheel guards and another person

lowering armrests, both reported at the same time but requiring two visits and two technicians. (This would exclude mechanical/motorised parts which needed to be returned.)

Agreed response times for repair and maintenance have also been left out of the Action Plan.

PPM programmes are warmly supported – for all, as is an extended out-of-hours repair service is strongly supported.

Families raised the issue of privately purchased wheelchairs and their maintenance. A better range of designs available on the NHS would reduce the need for private purchase. Some families have become desperate and vulnerable to unscrupulous traders. They are unsupported currently by NHS advice if they purchase privately and do not get help with maintenance and repairs. This must be addressed. Top-up arrangements would be welcome. It is particularly difficult to raise funds for adults as opposed to children.

#### Repairs and Maintenance:

A priority system is needed, taking into account level of dependence on wheelchair, personal circumstances.

#### **IT and Information Management**

A modernised IT system should be used to organise regular reviews for users and carers.

It could also provide a central register of users, including those who purchase privately. A registration card system at point of purchase would establish the extent and nature of private wheelchair use and help to recognise the requirements of those whose needs are not being met by the NHS.

#### **Quality and Governance**

PAMIS supports the establishment of a co-ordinator for wheelchair provision in each NHS Board. An annual report should be produced by each NHS Board and be published. Performance should be overseen closely by the WSS Project Board on behalf of the Scottish Government.

Clinical standards and criteria for provision of equipment should be readily available to all stakeholders. The issue of attendant propelled powered chairs should be addressed as a national matter of social policy and justice

PAMIS would also like to see independent monitoring of wheelchair and seating provision including the private sector. An important contribution to this process can be made by user and carer groups within the voluntary sector.

The role of the WSS Project Board is very important in relation to quality and governance. It should develop a range of means of two-way communication with users and carers, and increase their representation on the Board.

Jessie Roberts, Senior Co-ordinator, PAMIS 30 October 2008

*(Families' views were recorded by Michelle Morrison, South Lanarkshire Co-ordinator, PAMIS, on 4<sup>th</sup> September 2008)*