Health, Wellbeing and Local Government Committee

HWLG(3)-04-10-p3: 4 March 2010

Inquiry into Wheelchair Services: submission by Dr K Fitzpatrick, chair Posture & Mobility Steering Group (PMSG)

[PMSG aims to be an exemplar of Partnership in Healthcare - real service-user engagement (as yet under-developed in this context) - and is an advisory group to HCW on the wheelchair service throughout Wales. Representatives from across Wales are members of this group.]

Background

In 2001, in response to the Audit Commission report (2000), a project was initiated by the then Commissioner (Specialised Health Services Commission for Wales) to consult with wheelchair users and organisations representing disabled people across the whole of Wales. Its purpose was to examine the future of the services provided, and brought together service providers and service users. Facilitated by the University of Glamorgan's Welsh Institute of Health and Social Care, it offered the opportunity to explore and expand on users' views of the service.

This consultation resulted in a detailed 5 year Action Plan, which really took account of the concerns of wheelchairs users and carers/support workers. It was viewed by users as the route to a major step-change: the Action Plan would provide the basis for the eradication of so many long-standing complaints and so much dissatisfaction.

As part of the delivery of that 5 year Plan a Posture and Mobility Steering Group (PMSG) was set up in the autumn of 2004 (Terms of Reference attached at Appendix 1) to provide advice to commissioners, providers, external contractors and others, on the full range of issues within the Plan, including for example, the prioritisation of issues to be addressed.

The PMSG meets quarterly and is not simply a 'user group' but brings together user representatives with providers, commissioners of wheelchair services and others, and is chaired by a wheelchair user. The group consists of:

wheelchair users representative of various impairment specific groups

representatives of carers groups/interests

the directorate managers of the North and South Wales services

representatives of the Rehabilitation Engineering Service

others (e.g. external approved repairer, technical staff, medical staff)

PMSG has invited representations from associated and relevant groups or bodies, disability groups (e.g. Disability Wales has been represented for all of the lifetime of the PMSG), impairment organisations, third sector organisations, etc.

Unfortunately, although a sum of £30k p.a. was expected to be invested in its work, PMSG has operated without any dedicated funding since 2004, as the 5 year Plan was never fully implemented. The work has been supported through the budget and auspices of S Wales ALAS, with HCW support. This has frustrated a process which is nevertheless an exemplar, insofar as is possible, of the nature and value of true Partnership in Healthcare, demonstrating cost-benefits (major cost savings far greater than expectations/better outcomes/better service provision). This has been the result of some real service-user engagement in scoping, designing and helping to determine delivery of services.

The 5-year plan recommended (in summary):

research/needs assessment be undertaken to determine future demand and inform commissioning (NPHS)

wheelchair user involvement be strengthened (£30k support/discussion by end 2004)

arrangements for children, inc discussions with Whizz kids and others (£500k 2004-5, £300k in subsequent years)

formal commissioning advisory machinery (by March 2005)

appointments - Senior Project manager/therapist (Training and roll-out) (£30k 2004-5; £60k 2005-6)

Research and Development post (£50k)

Discuss short-term loan arrangements with local communities

Service standards (first tranche end 2004; second March 2005)

Unified assessment process with Rehabilitation Engineering

Plastic surgery (£150k committed 2005-5) investment to look on pressure sore prevention

'Voucher scheme' top-up funding revisited (rejected by Welsh disability groups in mid-1990s) - mixed funding approach to be explored

Investigate routine provision of lights on wheelchairs

Celt wheelchair replacement programme (£750k)

Pre-planned maintenance programme

Information system replacement (£110k recurring)

ALAS sign-posting e.g. to Disability Wales

Advocacy support and client-relations

Clinical leads/Rehab Consultants to be appointed

Title of 'Artificial Limb and Appliance Service' to be reviewed

Funding matters external to ALAS and the review of wheelchair services created a very different situation in a short space of time. By end 2004 it began to emerge that the major funding commitments could not be met, and that HCW was required, like other part of the NHS in Wales, to make service and efficiency savings.

In the light of the financial regime since 2004, it is to everyone's credit that so much of the 5 year plan has been achieved. It is clear that service users have been disappointed in some areas. Staff morale in the service has also suffered adversely.

Achieved:

Rehabilitation Consultants; senior therapist lead and training (Level 1 roll-out); Celt wheelchair replacement programme; Rehabilitation Engineering development and collaboration; pressure sore prevention work; unified assessment process; IT system replacement; sign-posting/information provision; PMSG implementation (including: investigation of lights and top-up funding issues; other user involvement (e.g. contracting processes)); mixed-funding/work with other agencies (e.g. Whizz Kids); Approved Repairer contract replaced/brought in-house.

Not achieved:

NPHS research; separate paediatric initiative; short-term loan arrangements; more explicit service standards; ALAS title change.

Planned preventative maintenance for powered chairs was part of Approved Repairer contract (outcomes not as expected).

Commissioning arrangements await outcome of NHS re-organisation and Ministerial Review (Stage 2 planned).

Current position:

In light of the recent challenges posed re-organisation, PMSG recommended:

Division between Health and Social Care -'joined up' working arrangements to be re-configured

Delivering part of the health agenda through accountability of LAs

Single commissioning body - no 'postcode lottery' - benefits of economies of scale in resources and accumulated expertise to all service users

More attention to the critical need for partnership working with service users for better health outcomes and the delivery of world-class health (and social) care in Wales.

The notion of partnership working does not undermine and should not be seen as undermining, the critical nature of clinical input. Rather it builds on the model of 'medical "input"' and seeks to replace previous medical models, to the benefit of both healthcare service user "and" practitioner. Enabling people to become confident about actively managing their conditions can only have positive cost-benefits and encourage users of scarce services to do so responsibly and wisely. Being confident about self-management in relation to one's health is at the same time empowering and allows the relationship of people and practitioners to grow into to mature decision-making where the "primary" decision-maker is the service user.

PMSG is committed to the view that all users must have responsibility for making decisions about themselves, exercising choice and control over every aspect of their lives. But this" fundamentally" requires that service users are afforded the tools and instruments of their own independence. Health inequalities may not be entirely eradicated but the current picture can be hugely transformed by partnership working.

Discussion

For every wheelchair user, children and adults, damage and/or failure of parts influence their lives immediately and in the most debilitating fashion.

Every effort which approaches a guaranteed high-quality service to wheelchair users is therefore vital.

The inquiry of the committee has focussed on the provision of services to children, for which recurrent funding was envisaged in the 5-year Action plan (£500k in the first year (2004/5) and £400k in subsequent years). This would have supported the work towards the (then forthcoming) NSF for Children, and actually pre-dated the NSF targets specifically mentioning 6 weeks from referral to assessment plus 8 weeks to delivery of wheelchair (unless the individual child required very complex adjustments).

PMSG must pay attention to adults, as well as children and young people, who use the wheelchair service. We have understood the user profile to have remained fairly static at (roughly) 20% of users who have what are described as 'complex' needs and 80% are standard wheelchair users.

The 20% group require specifically prescribed wheelchairs the operation of which can be affected by even tiny measurements - for example if a caster wheel is out of alignment by millimetres, the wheelchair's function can be seriously compromised.

These 'high-end' users will be the most threatened and vulnerable, requiring the greatest proportion of resources and emergency/urgent responses.

The 80% group of users of standard wheelchairs are more easily served and do not usually have a problem with the service they receive, and although we do not want to diminish their needs in any way, we concentrate here on those who have the most complex needs.

PMSG shares the aspiration that all users of complex equipment, children and adults who have the 'most urgent needs', should have those needs met as quickly and as well as possible. It is also true however that those are the most complex needs to meet and therefore require the most complex responses, and that delays are not always in the gift of any single, one of the supply chain 'links'.

Thus PMSG welcomed the recent Ministerial review, and announcement of a further, 2nd Stage of that review, believing that a whole-system analysis is necessary to rebuild the plans of 2004. But if we take the Scottish example, it is likely that we will need to see a doubling of current levels of funding to achieve our shared aspirations.

The 5-year plan - some details

Principles

The primary principles that the 5-year plan 'A Gateway To Greater Independence And An Improved Quality Of Life' adopted, after the consultation exercise with wheelchair users were:

To maximise ability and minimise disability

To take an holistic approach to improving the lives of disabled people

To work together towards this aim

These principles were underpinned by the views that wheelchair users should expect to be the focus of the service, with a 'major input' into their statement of need. This empowerment approach is what is described above as a true 'Partnership in Healthcare'. It should include lifestyle assessments, the needs of carers, be forward-looking and be equitable throughout Wales. Joint-service provision towards better outcomes has long been an aspiration, defeated more by circumstance rather than effort. Information was, and remains, a key element of enabling users to develop capacities to influence service design and prioritisation. A unified referral process and clear, published eligibility criteria were also deemed crucial.

Choice is the central requirement most often denied to disabled people and naturally figured large in the consultation and a greater range of choice of equipment was high on the list of changes that many wheelchair users wanted to see. Wales now has the widest range of wheelchairs available.

The Wales-wide consultation with disabled people recommended a single criterion for eligibility to receive the service: anyone deemed to require a wheelchair (taken as for more that six months - i.e. permanent or semi-permanent injury) and who was registered with a GP in Wales (this accounted for cross-border difficulties that some wheelchair users with Welsh GPs experienced and it is worth noting that the Welsh service was recognised as better by people living in England but with Welsh GPs).

Complaints and perceptions of the service

Approved repairer

Historically, the part of the service which generated most complaints was the Approved Repairer service. Users have often not distinguished between the AR contractor and ALAS. This is wholly understandable, given that the person most wheelchair users will see is the 'technician' who turns up at their door to effect repairs. Private contractors have consistently presented wheelchair users with difficulties, failing to repair, failing to repair in timely manner, not holding stocks of even basic parts, training for their 'technicians', appointment time arrangements, etc. The private contractor has been the primary source of emergency repair and there have been consistent failings throughout the years in the service provision afforded by this route.

Many wheelchair users were consulted, as well as PMSG, at drafting stage of the most recent Approved Repairer contract, awarded 4 years ago. For example, Planned Preventative Maintenance was suggested and built into this contract. At contracting stage only 5 companies were deemed sufficiently professional for interview: one of those was not tendering for a whole-Wales contract, another was the previous contract holder who had generated many complaints while in contract. The current contract holder promised a great deal more than has been delivered.

PMSG has argued that an in-house provision for repair and maintenance would lead to better outcomes for wheelchair users. This has been achieved in S Wales (beg Feb 2010) and those outcomes are now expected.

Paediatric service provision

Provisions for child and younger person wheelchair users have also been the source of much complaint, the focus of this Committee's inquiry. In 2004, fast track arrangements were recommended for disabled children (and those with terminal illnesses) acknowledging the particular requirements of those two groups of users and the support needed to meet their needs. PMSG was and is clear about the need for this support, and recommended it wholeheartedly, but it requires further funding, which was never forthcoming.

Other submissions have pointed, quite rightly, to the need for highly trained and skilled assessors. There has been a shortage of trained professionals to recruit throughout GB. There is now a Senior Therapist/ Training Officer who has developed a new training programme, and roll-out of Level 1 is on-going leading, we believe, to better prescribing and assessment outcomes in the near future.

Lifestyle

Lifestyle issues were highlighted by users, during the consultation process, as a very important aspect of assessment. There is a continuing need for further discussion of the scope of ALAS service provision. Needs (especially clinical) have had to be judged alongside wants of individual wheelchair users, within the current resource frame. Lifestyle issues remain important and appear to be figured into clinical assessments, where possible. Indeed, from one point of view, it almost impossible to conduct a professional assessment without taking lifestyle/needs into consideration. That is different from saying that not all lifestyle demands are or can be met.

For example, Wales has the greatest range of wheelchairs (colours, shapes, sizes, adaptability) available and a Rehabilitation Engineering service to call on for bespoke solutions. But this range is influenced by many factors including the industry suppliers who, for example, do not always put forward all the chairs in their private range for contracts with ALAS (preferring profit in the private market place). Incremental changes in pricing by private suppliers are not sufficiently funded, nor are other cost pressure resulting from the globalisation of this market. The contracting process for the current range of wheelchairs was a long and complex one. PMSG (represented by Chair) was heavily involved, and there is at least one negative view of industry behaviour which seeks to maximise profit at the cost of the lifestyles, pockets and lives of those who are forced to rely on wheelchairs for their mobility needs.

PMSG has done some work with user groups to explain the complexities of the contracting process and what is/is not inside the ALAS sphere of control. ALAS is limited through funding levels, through the hosting Trusts' financial and procurement regulations, and other factors as above, to the range that currently exists. Although efforts are made to go outside the range where specific needs can be met, generally those factors, rules, industry behaviour, the failure of safety/suitability inspections and other considerations, determine what can be prescribed through the service.

User expectations are sometimes unrealistically driven, for example, by Internet 'shopping': a user might demand a wheelchair available in the US but which does not meet EU health and safety standards, and therefore cannot, in all conscience, be provided. (In a particular case, the seating canvas was not fire-resistant and users in the US were injured in accidental burnings.)

Other issues of perception of service

There are many other issues that affect the users' perceptions of the service: for example, the routine provision of lights and riser mechanisms. There is no extra funding for these and PMSG took the very difficult decision to advise HCW (in 2004) against routine provision of lights when it became clear that the resulting cost-pressures would have significant adverse impact on other parts of service delivery, including the paediatric service.

Joint funding has been a long-standing difficult matter. It has proved almost impossible to resolve given the existing arrangements for budget lines for health (NHS) and social care (local government arrangements) and education. Many failures have been at the hands of the different parties being unable to agree at the cost of outcomes for the disabled person/child.

Other factors impose unwanted constraints, for example, it is only in very recent times that the industry has begun to produce wheelchairs tailored to children's posture and mobility needs. Previously the industry simply produced 'down-sized' adult chairs. PMSG has also investigated (with the lights issue) the cost of reflective and brighter coloured paint work for chairs, particularly for younger users, as part of a review of lifestyle "vs" clinical needs assessment. The industry is responding slowly but reflective paint (in place of lights) was also discovered to have a significant negative impact on the whole service provision (at 2004 prices).

PMSG supports the whole-person approach, but PMSG has had to agree that the primary assessment of need, at current funding levels, can only practically be around posture and mobility requirements.

A voucher/top-up option

The notion of a 'Voucher Scheme' was rejected by disability organisations in the mid-1990s. The scheme would have allowed wheelchair

users to have the cost of an in-range wheelchair so that they could 'top-up' with their own money to buy the chair they desired. This posed significant problems in that it would immediately create a two-tier system (at minimum), where those with ability to pay would get better equipment. There are other issues inherent here but essentially PMSG remains committed to the principle adopted by the disability organisations that there should be a universal standard service for all wheelchair users in Wales.

The scheme, and indeed other joint-funding schemes, presented insurance difficulties. The question arose as to who was responsible for maintenance and how is that responsibility affected by warranties, untrained repairs (perhaps carried out by the user or family members), etc. When charities 'donated' a wheelchair to a user they did not usually take on maintenance, which was then an extra unfunded cost to the service when that user required support. There are probably quite a number of privately (or charity) funded wheelchairs, and it should be part of a research programme to determine how many and what likely impact there would be on the service if those funding privately decided to come to ALAS to replace and/or maintain their wheelchairs.

Short-term loans

Short-term loan of wheelchairs is not within the remit of the wheelchair service and is usually provided by other third sector organisation such as British Red Cross. The complexity of the 'whole picture' of providing wheelchairs needs thorough analysis. The situation is additionally complicated by the purchase of wheelchairs of a wide variety by e.g. hospitals, which are not to any apparent specification, are not properly maintained and endanger patient safety. Especially urgent is the matter of cross-infection and the possible absence of any deep-cleaning in hospitals after use.

Information and communication

PMSG was anxious to work on the information requirements of users and could have achieved a great deal here, especially through expertise from the lived experience of being wheelchair users and carers, but without any funding or capacity for even minimal research nothing near the communication aspirations of PMSG has been possible. Even the work and position of PMSG is badly misunderstood (one submission spoke of a 'user group' in S Wales, for example).

Condition management:

We have long argued that the users of services can adopt responsibility for the wise use of scarce resources. But the conditions must be created in which all the relevant information, the tools and support for entering the process, must be offered to enable users to better manage their conditions. Wheelchair users could, for example, be trained to do checks and low-level maintenance, to avoid being rendered helpless by many of the smaller technical problems that affect wheelchairs after use. This should be a joint responsibility; a real partnership between users/clinicians/ technicians/commissioners/providers/industry suppliers to the best outcomes for wheelchair users, and warranty matters should not stand in the way.

"NB: "There is a clear need for psychological support, especially to new users but also to existing long-term wheelchair users, to support their efforts to manage themselves. Access to such support has been developed in S Wales, as an exemplary step in service development.

The future

PMSG believes that the most effective and equitable service can only be delivered through a unitary service for Wales, embracing all the necessary elements of a seamless including for example the Rehab Eng service, and including other government agencies such as the Access to Work Scheme. Working relationships were begun with the Employment Service but resources dented the opportunity.

PMSG has also participated in Stage 1 (and recommended a Stage 2) of the Ministerial review of the wheelchair service, and welcomes for example, the recommendation that there be a Policy Lead in WAG. This position could help enormously with many of the other pressures PMSG is aware of such failures/delays in the supply chain. PMSG has sought opportunities to have user input valued as highly by the industry as it has become valued by HCW "et al".

Notwithstanding the successes achieved in the face of the financial landscape PMSG is committed to the further development of wheelchair services to meet all the needs of users in the most timely and appropriate manner. The consultation exercise report (the 5 year plan) reflected the belief that remains, that the best outcomes for wheelchairs users will only be achieved through a holistic approach to the lives of individual wheelchair users. Insofar as it is possible to remove some of the resource constraints, PMSG would strongly advocate that the review process be continued to scope and identify with user partners, the resources required to deliver the service all wheelchair users in Wales deserve. Unnecessary and avoidable delays in assessment and supply of wheelchair to individuals are not acceptable to anyone inside or outside the service, and whatever their position in the 'chain' and the user must, as the 2004 plan said, be the focus of the service.

Appendix 1

Posture And Mobility Steering Group

Terms of Reference (2004)

Purpose

The Posture and Mobility Steering Group (PMSG) brings together users and carers, commissioners, rehabilitation engineers, service

personnel of the Artificial Limb and Appliance Service (ALAS) and other professionals as appropriate. Its purpose is to take forward issues identified in the five year strategic action plan for wheelchair services developed by the Commissioner of the Service, Health Commission Wales.

At a point in the future there may be the opportunity to extend the terms of reference to include other users of services within the ALAS.

Membership

Membership of the PMSG will be approved by the Commissioner HCW who will also be a standing member, and will include:

Wheelchair users who will be, where possible, a representative from:

Disability Wales
Younger People
Older People Groups

Impairment specific groups such as Motor Neurone Disease, Multiple Sclerosis, Cerebral Palsy, Spina Bifida, Muscular Dystrophy, Spinal Injury, Acquired Brain Injury, Arthritis, Amputees, Users with a Learning Disability

There will also be appropriate membership reflecting/representing the views of carers.

The Service will be represented by:

Centre Manager South Wales
Centre Manager North Wales
1 Medical Consultant
1 Clinical Lead from the service
1 representative from the Rehabilitation Engineering Services

Discussion will be held with other organisations to be represented on an ad hoc basis e.g.

Social Services
Education
Other professionals using the service
General Practitioners
Associations of health professionals (eg. OTs, Physios)

The group may agree to add to this membership list as it feels appropriate.

Members should understand and be able to apply the social model of disability in appropriate contexts.

Members should be able to represent, the views of their specific grouping and/or service area

Members should be able to represent geographical spread across Wales

Members of the group must make a commitment to participate as fully as possible in the work of the Group and the implementation of the action plan, including attendance at meetings, and work outside those meetings.

Membership should be balanced and represent a cross-section of interest

Chair

The Chair will be a wheelchair user, and shall be appointed from the Users Representatives by and in agreement with the Commissioner. Chair shall be appointed for one year, and then the appointment will be reviewed.

Secretariat

The Commissioner has identified a sum of money to support the work of the group. Secretarial support will be funded from this budget.

Membership expenses

User representatives will be reimbursed for their travel expenses and other legitimate expenses that they occur because of attendance at the meeting. They may also receive an honorarium. Employees of other organisations shall normally be exempt from honaria, travel or subsistence payments.

Frequency of Meetings

Meetings will usually be held quarterly, but may be held more frequently as the agenda demands.

Quorum

Meetings will be deemed quorate where 2 user representatives and 2 service representatives are in attendance.

Status

The PMSG is an advisory Group to Health Commission Wales, as the commissioning body of Wheelchair services in Wales, and to ALAS and the NHS Trusts as provider of all aspects of the wheelchair service.

Role and responsibilities

The PMSG will discuss and make recommendations to the Commissioner and the ALAS on specific areas of development contained within the action plan for wheelchair services.

It will develop a work plan to address the issues that are within its remit.

These areas are defined in the plan and include:

Recommendations on standards of service delivery
Recommendations on equipment provision
Views and recommendations on changes to the way the service is delivered
Contribute to discussions on the awarding of external contracts to deliver areas of service and provision of equipment etc as per action plan

The PMSG will provide a forum for Service Users, to relevant health professionals and ALAS personnel to work together.

Members of the group will acknowledge that they each represent the views of a group of service users or personnel and will strive to give a corporate view from that group. The group is not a forum for individual perspectives on service provision, except insofar as they might illustrate the wider view.

Individual members will be expected to fully participate in the work of the group and will be required to contribute to specific pieces of work.

The group will recognise that its aims and aspirations must be in line with the aims and aspirations of the Service and its Commissioner.

Delegation duties

The PMSG is able to set up 'task and finish groups' as it is appropriate to take forward specific pieces of work, in line with the action plan. The PMSG will take advice from its members as to the appointment of individuals to the task and finish groups, which will report back findings to the PMSG and any recommendations must ratified by the PMSG as a whole.