Health and Social Care Committee One-day inquiry on wheelchair services in Wales Sue Hurrell - WC 2

I live in Cardiff and have a 6-year old daughter who has cerebral palsy and uses a wheelchair. We purchased our own powered wheelchair about 18 months ago, but our daughter has a manual wheelchair from ALAS and we have had several interactions with the service during the past year.

I wanted to respond to this consultation primarily because I feel there needs to be considerably more information in the public domain on the performance of the service. Most families will probably only have one or two interactions with the service, and waiting times etc will be specific to that case - so it is difficult for individual users to judge whether the service is improving overall.

Our own experience over the past year is rather skewed by the fact that an unfortunate decision was taken in November 2010 that led to the wrong wheelchair being provided (8 months later, after delays). Another review was scheduled (rapidly) and a new chair, which has dramatically improved our daughter's mobility, was provided in January 2012. We are very happy now, although it is a pity we were not able to reach this outcome in less than 14 months from the first review. I should also say that we have always found the individuals we meet at the service to be thorough, helpful and committed to meeting our daughter's needs. We have also been happy with the maintenance arrangements since the contract with Serco came to an end (nobody ever answered a telephone at Serco). Happily the new arrangements are far more responsive and we have been well-served on the whole. Our daughter has also attended her third wheelchair training session, this time with Whizz-kidz. This was an invaluable opportunity to meet and discuss with the ALAS team and for our daughter to spend time learning with other wheelchair-using children. We rate this element of the service very highly.

As well as being a parent of a service-user I also attended a meeting in Cathays Park in a professional capacity (I work in Value Wales - the Welsh Government's procurement arm) at least a year ago now, where a wide range of professionals and representatives of support organisations were all consulted on a set of projects underway to improve the service. I am sure these all concluded and the results were implemented, but I do not recall seeing any follow-on material or being invited to any further meetings.

Turning to the recommendations of the committee - the first seven or so call on the Welsh Government to draw up a service specification and a strategic plan with particular features. I have not been able to find any evidence of these. Other than the announcement of more than £2m extra funding for the service (to double the number of clinical staff assessing individuals and reduce waiting times) there is not a great deal to be found on either the Welsh Government or ALAS websites. Several of the others are around waiting times and joint working, but there is little evidence in the public domain of improvements here. It would be very helpful if stats on waiting times, expenditure etc from the service were published annually - maybe they are, but I was unable to find them. It would be good to know how this extra £2m has been spent and what the outcomes have been.

Recommendations 8 and 9 are, in my view, some of the most important. Our own experience over the past year does not suggest that the communication process has changed dramatically. What is needed (as suggested in recommendations 9 and 13) is an on-line system that allows those waiting to be able to track the progress of an order. Failing this, new users should to be given written explanations of the process and estimated timescales. I feel the onus is still, generally, on the service user or parent to phone and chase up on progress. The approach (typical for the NHS in general) is still rather too much about being a service user, rather than a customer, and waiting patiently until you are told what is happening. The reality is that most people are far happier if they are kept informed about reasons for delay.

Sue Hurrell