



Wheelchair Services Meeting

29th September 2010



Apologies: Gwen Pearson, Beryl Perrin, Brenda Bartlett, Kathryn Sudbury.

Attended by:

Chris Morris (Chair) Helen Aplin (physio and head of wheelchair services Exeter Mobility Services) Donna Beswick (parent) Amy Francis (parent) Ginny Humphreys (Head of Therapy at Vranth House and district Head of Paediatric Physiotherapy) Tony and Marian Gilbert (parents) Jeannette Kemlo (parent and chair of Parent Carer Voice) Ruth Prouse (parent and nurse Vranth House) Val Shilling (Cerebra Research Unit) Elaine Wells (Professional Lead for OT in Devon, Ellen Williams (parent)

Purpose of this meeting:

1. Wheelchair services for disabled young people, and in particular the service to special schools was raised as an issue by a parent. This was an initial meeting to bring parents and health professionals together to gather information and views on the current service.
2. To decide with parents and health professionals whether this is a topic that we can take forward as a research unit or whether this is a service related issue requiring a different course of action.

Issues raised included:

Accessing service – limited clinic availability in the service provided to schools

Involving parents in service design

The appropriateness of the equipment e.g. lack of choice and failure to meet need

Reassessment/review of equipment – wheelchairs are not subject to the same 6 months tests that slings and hoists are

Frustration at the difficulty of getting the equipment needed in a timely fashion – parents sometimes turn to private and charity funding

Getting the correct equipment is sometimes felt to be a fight where parents have to justify everything they are asking for. The service is restricted by budgets and cannot afford to provide everything that they are asked for – personalised budgets for the individual child may go some way towards changing this. There are separate contracts for wheelchairs and for equipment which can sometimes make it difficult to understand how the service works.

There are broad reaching implications for example:

Risers for electric wheelchairs to allow access to work benches and desks thus meeting an educational need are not seen as a health need and are not covered by the NHS

Limitations of equipment mean that families sometimes can't function as a family e.g. walking the dog together in the countryside, or going on the beach

Wheelchairs are central to inclusion; inadequate wheelchairs potentially limit young people's opportunities for being included.

Evaluation:

A national and SW regional review of wheelchair services is currently underway. There is considerable diversity across region as to what is provided and it is hoped that the review will draw services together. The national review is looking at equipment and procurement however it is not known whether or not parents are being involved in the review process. Recommendations from reviews still need 'buy in' from commissioners.

Involvement:

Exeter Mobility Centre has a wheelchair user involvement group run by users. This currently is mostly attended by adult users however there is the possibility of a separate user group for young people and their carers. The current group approaches the commissioners themselves (wheelchair services aren't part of children's services and are commissioned separately).

In physiotherapy and OT parents and children are able to feed into the service to some degree through participation in forums and sitting on interview panels.

Information:

Families will often take spanners to the chairs themselves because of the limited capacity of the service to conduct a review service. However, parents can self refer to a clinic; they don't have to wait for their physio or OT to refer them. This is not necessarily known by many parents.

This point led to a broader discussion about how to disseminate the vast amount of information that families need without necessarily using websites; something similar to the Family File in this country or the Canadian Keeping it Together (KIT) which holds pertinent information and contacts on topics relevant to that family was discussed. JK noted that a review of information services is being led by Beryl Perrin. Organisations such as Friends and Family in Plymouth and Parent Carer Voice provide a medium for the spread of the informal network of knowledge that parents have. This network and knowledge could perhaps be harnessed in some way to work efficiently.

As the issues raised are essentially service issues it was felt that the key to taking these issues forward is for parents to be involved in the service review that is currently ongoing to have a say in how the service is organised.

Actions:

HA or JK to find out who is organising the South West review. Parent Carer Voice in Devon and possibly Parent Partnership in Plymouth to seek parent involvement in the service review.

HA to pass on the contact details of the wheelchair user group – parents may wish to join or discuss setting up their own group

Link to Kennedy report for info:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119449

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119446.pdf

Link to KIT:

www.canchild.ca/en/canchildresources/kityouthkit.asp