



PaCConnect

Wheelchairs and equipment – 8th January 2014

Professionals: Ann Dyson, Centre Manager, and Lucy Marshall, senior wheelchair therapist, from Sussex Rehabilitation Centre, Brighton General Hospital. Bridget Morden, Head of Occupational Therapy at Seaside View Child Development Centre, Brighton. Simone Lane, Brighton & Hove City Council Clinical Commissioning Group - children's wheelchair service.

Ann Dyson manages wheelchair services: there are around 6,000 people (children and adults) service users in Brighton and Hove, Lewis and East Sussex. Ann's team assesses clients in both homes and clinics.

Lucy Marshall, senior wheelchair therapist, works alongside 2 other OTs and 2 Rehab Engineers. Assessment and review of clients referred from GPs or specialist services, the team can receive as much as 30 enquiries a day. Each referral is reviewed via a duty system whereby they are triaged in terms of clinical need. About 85% are dealt with by direct provision and around 15%, a more complex category, are dealt with more assessments at home or in clinics. The team prioritises the terminally ill and those awaiting discharge from the acute sector. We have about 6,000 clients – 5% are children.

Bridget Morden is head of Occupational Therapy at Seaside View, her team deals with a wide range of age; occupational therapists assess provision according to necessity and they are not involved on provision of wheelchairs.

Simone Lane works with the Clinical Commissioning Group in Brighton and Hove, a GPs lead body which holds the budget and commissions NHS services. Simone mainly works with people at end of life care, eg. stroke, looks at the evidence and put together a strategy by looking at pathways, how people move through services. The body is responsible for wheelchair funding; it has many priorities and wheelchair users are on the list. Her work also focuses on better understanding of service users.

Key Issue / Question	Suggested Solution / what parents would like	Agreed action/ date/ who
<p>Assessment and criteria:</p> <p>Q: Wheelchair services look at the clinical posture of the wheelchair users but what about the health needs of the carer and the social needs of the child and their family?</p> <p>A: We rely on information we get at time of referral. The assessment stage has improved and parent's perspective is taken into account.</p> <p>A: Health care and social care have started working more together, hopefully changes will be coming; there will be more focus on integrating services.</p> <p>Q: The first wheelchair assessment for a child who has never been in wheelchair before can be challenging (It is the same assessment for adults as it is for children). The child may not be able to demonstrate the skills within the time of the assessment that are deemed necessary to justify having a lightweight manual wheelchair. There are concerns that a child who is mainly dependent on a self-propelling wheelchair to get around will not be able to proficiently be able to manoeuvre the chair or learn skills such as getting up and down a kerb if the chair is too heavy. If self-propelling isn't optimised there is a risk that the child will become passive and rely more on adult propulsion thereby negating his or her independence. One of our parents told us the family bought their daughter a Panthera which is a more lightweight wheelchair than the Action Junior, (and is part of the core offer in several areas of the UK). She can now wheel and manoeuvre independently, something she would never have learnt to do in the heavier standard issue Action Junior the child previously had, which was too heavy and cumbersome for her due to weakness caused by cerebral palsy.</p> <p>A: We are running the Panthera scheme – mentioned later in this document.</p> <p>A: The team knows that the approach has to be more holistic</p>	<p>S: Could there be a more holistic approach? One that takes into account the social needs of the child and the social and physical welfare needs of the child's carers?</p> <p>S: Can Wheelchair Services look at increasing stock of outgrown, refurbished privately bought wheelchairs? Perhaps work with suppliers to provide parts and expertise etc in exchange for preferred provider status?</p> <p>S: All parents were happy to give their child's outgrown wheelchair to Wheelchair Services, even if privately bought, if it meant Wheelchair Services could offer more choice.</p> <p>A: We cannot accept private wheelchairs as stock because we do not know their repair history. **Also, AJM are contracted to repair only certain makes and models. To extend this, would be costly. As yet, we have no indication of any proposed funding increases to enable us to widen our provision.</p>	<p>The team have to meet the clinical need first and will try to look at wider issues where possible/feasible.</p>

<p>as the 'real' situation is more complex. The criteria are concerned with ability, comfort, posture, environment, medical history and a whole range of other issues.</p> <p>Q: A child is deemed suitable for a power chair only if the child needs powered mobility in their own home, and if the home environment is suitable for a power chair.</p> <p>A: Not exactly, to be eligible for a powerchair assessment, an applicant must be unable to walk or self-propel in their own home, be able to use the chair independently and have a suitable home environment at the time of their application.</p> <p>Q: There are concerns among our parents that the environment where the assessment takes place is not realistic as it takes place indoors on a smooth surface with no obstructions. Therefore a child that can use a manual chair indoors but who would find it difficult to use outdoors would not be eligible for a power chair.</p> <p>A: That is correct, if an applicant can self-propel in their own home, they are not eligible for a powerchair assessment. Charitable funding may be sought for outdoor powerchairs.</p> <p>A: When we assess the eligibility for power chair, we assess how the child moves to engage with other people, something like take him/herself to a different room in a suitable home-environment. It is not possible to prioritise outdoor functionality. Also it gives the child chance to develop self-propulsion skills.</p> <p>Q: Some of our families think the assessment is too short.</p> <p>A: The team is doing its best to have a more holistic approach. We look at the complex needs and the medical conditions that impact on the child's mobility. We have recently acquired two Panthera wheelchairs which we are loaning out to children so we can assess them with lighter weight wheelchairs. We hope to be extending this project in the future.</p> <p>Q: Who decides what the child needs when he/she grows?</p>	<p>S: WS are working more closely with OTs to ensure that children who need a powerchair, but whose home is unsuitable, is rehoused or their home is adapted in order that the child can have a powerchair.</p> <p>A: We can suggest this to the appropriate services, but we have no authority to make it happen.</p> <p>S: It would be good to extend the criteria to outdoor practice too.</p> <p>A: If child shows the potential to self-propel outdoors, then this will be included in the assessment process.</p> <p>S: Parents could fill in a form to contribute to the assessment not just the OT, explaining why a power chair would be beneficial for social reasons.</p> <p>A: All powerchair applicants fill in a self-assessment form where such information can be imparted.</p> <p>S: More information and clarity around criteria</p> <p>A: We aim to put our eligibility criteria on our website.</p>	<p>WS to help support parent carer's application to charity funding for powerchairs.</p> <p>A: We have an information officer who can help with this.</p> <p>It was suggested that PaCC/parents could work with service providers on making the assessment better.</p> <p>A: It is important to note here, that</p>
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<p>A: A new assessment will be required</p>	<p>However, it is a publically available document and parents can request a copy.</p> <p>S: To involve the parents more A: All parents are invited to be part of the assessment process. We do not assess children in isolation.</p>	<p>the debate is switching between powerchairs and high performance manual chairs. These involve very different assessment processes, levels of disability and clinical needs.</p>
<p>How does the wheelchair offer work? What's available locally?, Local Offer (LO)</p> <p>Generally wheelchair services have a very limited choice of wheelchairs. For children there is currently usually only one manual and one power chair offered. Assessment and subsequent offer is based on clinical, i.e. postural, need.</p> <p>It is of major concern to our parent carers that using heavier attendant controlled manual wheelchairs has an impact on the carer's health; most carers are on pain killers because the work they do on pushing the wheelchair, as well as transfers, handling heavy equipment etc. This has serious long-term medical consequences and shortens the years of being able to be a carer. Carers also report that they don't walk as much as they would if the wheelchairs were easier to handle – they feel they must use the car rather than walk. This impacts directly on the health of the carer, and is not socially conducive for the client either. Brighton is hilly and carers pushing heavy manual wheelchairs are really struggling. With the new budget linking up health and social care, there might be a way that, for instance, add-on motors can be bought with the social care element of the budget and fitted to the NHS chair.</p> <p>Q: In order to address the failings of the NHS wheelchairs, many of our parent carers have had to fund privately bought wheelchairs themselves either from the household budget, through lengthy and arduous fundraising, or from charities.</p>	<p>S: More information about ways to adapt wheelchairs so they become easier to push. A: This is available from the Information Officer. Adaptation to NHS chairs usually requires permission from the service.</p> <p>S: Possibility of refurbishing used attendant controlled add-on motors? A: Powerpacks? Are not provided by the NHS, however permission is usually given for them to be fitted privately.</p> <p>S: Wheelchair Services to support application for add on attendant motors to Social Services or charities? A: We frequently provide explanation to charities and other funding bodies as to why we are unable to provide powered mobility to carers. Powered mobility can only be provided to those who are eligible</p> <p>S: Wheelchair Services to work with families and charities to help acquire wheelchairs that are on (extended) preferred supplier list via an extended voucher scheme. And to offer</p>	

<p>However, Wheelchair Services are currently unable to service or fix non-NHS wheelchairs.</p> <p>A: We have a limited amount of time to assess the potential of a child to use a self-propeller. However, the Panthera scheme is now running, so children will have longer to develop their potential</p> <p>Q: Why is there so little choice on the Wheelchair Services' preferred supplier list for children?</p> <p>A: There are many issues involved, for example, the greater costs involved with different companies. A lot of manufacturers are based in foreign companies (In Germany for example), and parts are difficult to replace. A lot of these lighter weight wheelchairs do not grow with the child and are therefore not cost effective, and our maintenance contractors are not trained to look after all different types of wheelchairs. We hear unfavourable reports of some wheelchair manufacturers too.</p> <p>Q: Why are attendant breaks not fitted as standard on manual wheelchairs?</p> <p>A: there are about 6,000 service users living in Brighton and Hove, a very hilly city. The team does its best to support everyone and factory and retrospectively fitted attendant breaks can cost a lot of money, in a lot of cases more than the wheelchair itself. The costs are huge and we have to prioritise clinical need. Families can put a case forward for brakes to be fitted which we can consider in some cases, but this may be another example of how the social element of the new personal independence budget might be useful.</p> <p>Q: Looking at ways for families to have more choice in wheelchairs our families were curious about the voucher scheme.</p> <p>A: The Voucher scheme is available for self-propelling chairs. Further information about the voucher scheme is available on</p>	<p>maintenance?</p> <p>S: More information for parents about Whizz Kidz, Go Kids Go, Association of Wheelchair Children Charitable etc wheelchair training courses.</p> <p>A: We have an Information officer. Also, all these charities are online too.</p> <p>S: Wheelchair Services are trialling two reconditioned Panthera wheelchairs with families at the moment.</p> <p>S: Perhaps look at whether there's a local bicycle refurbishment company could offer a retrospective brake fitting service?</p> <p>A: Fitting permanent accessories to an NHS wheelchair requires permission. Clients should be aware that fitting such brakes via an unknown company may carry a degree of risk. Applications for hub brakes can be put to the service</p>	<p>Ongoing assessment.</p> <p>Someone to research</p> <p>Someone to research shortlist of decent reliable wheelchairs with proven track record.</p> <p>A: We cannot advise on private purchases as we have to remain impartial. Also the degree of liability is too great.</p> <p>Someone to engage with a charity and work on a process.</p> <p>A: Most charities have long-established processes in place.</p>
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<p>request.</p> <p>Q: Can we look at extending the preferred supplier list of wheelchairs? A: We are currently looking at the Panthera scheme. It will be reviewed and if successful, the Panthera may be added to the list.</p> <p>Q: Can we look at extending the voucher scheme to enable collaborative funding of wheelchairs between public, charity and private? A: A voucher is issued to the value of the wheelchair to the NHS. The extent to which the client wishes to “top-up” this amount and where they get the funding to do so, is at their discretion.</p> <p>Q: Can we look at extending the voucher scheme to power chairs? We do not receive funding to do so. It is something we can raise with our commissioners but it is doubtful.</p> <p>Q: Maintenance contractors have a huge impact on clients and their families. A child can be without a wheelchair for weeks if something goes wrong and it isn’t fixed properly. Knowing what the carers’ rights are and what they can expect is important. Whilst a lot of our families are happy with AJ Mobility, some report very negative experiences. A: We are in the process of renegotiating our contract with AJM, once complete we will publish details of the level of service that clients should expect. A: Regarding charity waiting list: put your child on the list before he/she goes into adult age because as things are at the moment there are not really any charities that fund disabled adult wheelchairs. A member of the wheelchair services team, Carol Boyle, can give information on charities to parent carers.</p> <p>A: Be very independent; look around for what’s on offer.</p>	<p>S: Our families have indicated that they would be prepared to pay for the Wheelchair Services maintenance contractors to take care of their privately funded wheelchairs rather than pay for supplier. A: Clients can enter into a private arrangement with AJM to maintain their wheelchairs.</p> <p>S: Working more imaginatively with AJ Mobility could be of great benefit. Perhaps the wheelchair suppliers would be happy to train AJ Mobility for a place on Wheelchair Services preferred supplier list.</p> <p>S: Possibility to link to students who do research on these issues and also research funding. A: Again, we have an Information Officer to work with clients on accessing charitable funding.</p>	<p>Find out how much maintenance contract would cost per month. Contact supplier/manufacturer for their thoughts. A: If the Panthera was taken on board – this would be raised with our supplier at the time.</p>
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