

Health, Wellbeing & Local Government Committee

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Position paper: Health, Wellbeing and Local Government Committee of the National Assembly for Wales Evidence

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1. About Whizz-Kidz

Whizz-Kidz is the national children's mobility charity. We are the largest provider of powered and lightweight manual wheelchairs to children and young people outside the NHS. We support families who are unable to access the mobility equipment and support they need through statutory services. The majority of our beneficiaries are from low income families with a joint income of less than £23,000.

Whizz-Kidz works in close partnership with the NHS. We aim to build a culture of continuous improvement to deliver cost effective, high quality services that are centred on the needs of users.

There are 70,000 children and young people in the UK that have mobility requirements. We estimate that across Wales there are 3,500 alone. Whizz-Kidz has provided equipment to 114 children and young people in Wales including 49 powered chairs, 15 lightweight manuals and 8 specialised sports chairs. This still leaves 3,289 children and young people with unmet mobility needs.

The right wheelchair can enable a young person to get themselves a drink, take part in school lessons, keep up with their friends during school and playtime and make the most of spending time with their family - things we all take for granted.

2. Cost of not providing the right equipment at the right time

The shortfall in provision of effective wheelchair services for disabled children and young people across the UK has been widely documented, over many years (McColl report 1986; Audit Commission, 2000, 2002; Prime Minister's Strategy Unit, 2005; HMT and DfES 'Review of Disabled Children' 2007).

Families face waiting times of months, sometimes years, for the right wheelchair. Many are simply unable to access the wheelchair that meets their child's needs.

Ill-fitting or inappropriate mobility equipment can result in postural damage, the need for costly spinal surgery, and medication to relieve pain. Coupled with heavier reliance on services and ancillary support through personal assistants, this costs the NHS and Local Authorities time and money.

15% of young wheelchairs users are estimated to be at risk of spinal damage which could be avoided through the provision of a powered wheelchair with a tilt function.

If over 500 wheelchair users who require spinal surgery - at £4,000 per procedure and 50 days in hospital (taken from the national tariff) - were given the correct chair £2m in NHS costs could be avoided.

Providing the right wheelchair is essential in order to satisfy basic human rights, and is the first step towards achieving independent living in the future¹. It supports a child's ability to enjoy a full and active childhood, and enables them to participate fully at school, and to take part in social activities developing the skills and confidence they need in life.

Pressure sores can result in health costs of £4,000 and a hospital stay of 62 days (taken from the national tariff). Yet the provision of the right seating to mitigate pressure sores ranges from only £300+.

Powered mobility equipment can reduce a child's reliance on personal assistants because they do not need to be pushed and can develop their independence to do every day tasks. A personal assistant being paid the minimum wage, working a 37 hour week costs around £10,500 a year (plus the employment costs). Whizz-Kidz can provide a riser on a powered chair at the cost of approximately £1,000, which will enable further independence and freedom with every day tasks especially in school where desks of all heights can be reached.

3. Impact of Early Intervention

The benefits of early intervention for disabled children are well documented. There is evidence to suggest that disabled children under

the age of five can benefit significantly from using powered mobility equipment², but this can easily be overlooked in the early years stage, which can risk developmental delay³.

Early diagnosis and, more broadly, an understanding of the services and equipment they require to support them to achieve in different ways are critical to improving outcomes for disabled children.

It is widely believed that disabled children under the age of 5 are not capable of safely managing a powered wheelchair, despite evidence of the benefits of providing powered mobility equipment to this age group⁴. At times local eligibility criteria for powered mobility equipment may place a child outside the boundaries of statutory provision on the grounds of safety. Anecdotal evidence suggests that this may be a superficial reason, which is applied in order to manage a tight local budget. Given the safety features built into mobility equipment (dual control function) it would seem fair that the duty of care of the parent still remains, whether the child is disabled or not (just as the same rule applies to a guardian doing all in his/her power to prevent a child from running into the road).

Whizz-Kidz recently completed a piece of research into the benefits of powered mobility for disabled children under the age of 5. The evidence within the report strongly supports the case for early intervention in the provision of the right wheelchair, as this can have a profound effect on a child's life chances⁵.

4. Case Study

Rhiannon is 13 years old and lives in Swansea. She is a sociable thirteen year old who loves going to the cinema, shopping and listening to music. She lives at home with her mum, dad and five year old brother and attends the local comprehensive. Rhiannon has the condition cerebral palsy which for her means she is unable to walk and cannot propel a manual wheelchair. Her current wheelchair is slow, bulky and unable to cope with slopes, kerbs and uneven surfaces. The seating is also very basic and doesn't give her the support she needs.

The NHS had provided Rhiannon with a powered chair since she was 6 years old. Unfortunately, the chairs provided were never suitable or comfortable for Rhiannon. Many different methods to make the chairs appropriate for Rhiannon were used. Rhiannon's wheelchair services eventually admitted that they did not have the budget to provide what Rhiannon needed and suggested that Rhiannon's parents contacted Whizz-Kidz. Whizz-Kidz has now provided Rhiannon with a powered wheelchair with riser function and specialist seating suited to both her clinical and social needs. A specially trained Whizz-Kidz therapist assessed Rhiannon and allowed her to test a range of equipment and then decide together which would be the best wheelchair for her needs.

The new wheelchair enables Rhiannon to keep up with her friends and family and join in with all the things teenage girls love to do. The riser function also enables her to elevate herself to reach things and speak to her friends at their eye level at the push of a button.

Before Rhiannon received her chair she told Whizz-Kidz:

"I will be able to go up kerbs, to the shops, onto the beach and rise up to speak to my friends at their eye level. I can't wait!"

5. Working in partnership with the NHS

Whizz-Kidz is working with partners in the NHS to pioneer a new approach to wheelchair provision, based on efficient use of limited resources, smarter procurement practices, and the highest standards of care that address the holistic needs of every disabled child and young person. A partnership between Whizz-Kidz and Tower Hamlets Primary Care Trust has given local (300 approx) children and young people access, for the first time, to appropriate mobility equipment and wheelchair skills training, that meets their complete needs in school, at home, and at play.

The partnership provides advice, equipment and support from a child's early years right through the transition to adulthood, enabling them to live more independently in the future.

Since April 2008, when Whizz-Kidz became the lead provider for children in Tower Hamlets, we have seen and assessed 441 children and young people and provided 212 pieces of equipment. And we have managed to virtually eradicate the waiting list - in most cases children and young people are invited to an assessment within 2 to 4 weeks of referral.

Since September 2008, Whizz-Kidz has been running regular clinics within the three main

special educational needs schools which cater for the majority of children and young people with disabilities in Tower Hamlets. The informal feedback provided to us by the therapists and teaching staff within these schools is that this is an affective approach to providing our service, which reduces the amount of time these children and young people are out of school for appointments. It also aids the assessment process for all, as a thorough gathering of data can be completed, taking into account the opinions of all relevant persons involved in users' care.

Whizz-Kidz surveys children and families using a 12 item outcomes measure that assesses user satisfaction with both the equipment and the service that the user has received. The survey is carried out using the "Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0)". Last year the Tower Hamlets project received a satisfaction rate for equipment of 100%.

Whizz-Kidz has also worked closely with corporate partners to drive through efficiencies and to become more effective. Working with buyers from Tesco we have developed a procurement strategy that means we are able to provide more disabled children with better equipment and at prices better than those available to the NHS. Also, a team from Accenture has helped us develop lean processes that

mean, very soon, we expect 70% of children seen by our therapists to be able to take home the equipment they need on the very day of the assessment.

Whizz-Kidz' award winning partnership with Tower Hamlets PCT was recognised in the joint DH and DCSF Child Health Strategy (Healthy lives, brighter futures: the strategy for children and young people's health). The Child Health Strategy also announced a new partnership between Whizz-Kidz and the London SHA to improve joint commissioning with the local PCTs.

Since Autumn 2009 Whizz-Kidz has been working with Outer North East London Community Services to provide paediatric mobility services for children and young people in Havering, Barking and Dagenham and Brentwood. We are in discussions with many other PCTs across London and the UK to look at how the model in Tower Hamlets could be rolled out in their areas.

1 Services for Disabled Children, Audit Commission, 2003, p34

2 Don't push me around! Disabled children's experiences of wheelchair services in the UK, Whizz-Kidz and Barnardo's, 2006, pg 8 & pg 15.

3 Improving the Life Chances of Disabled People, PMSU, 2005, p116

4 Powered Mobility for Younger Children; the significance of powered provision for children under 5, Whizz-Kidz, November 2000.

5 'Watch your toes Mummy', Whizz-Kidz and Millward Brown, March 2008.