



**All Party Parliamentary
Group for Paediatric
Wheelchair Reform**

**“My wheelchair
is my shoes”**

Making the case for
wheelchair reform

June 2011

Members of the All Party Parliamentary Group for Paediatric Mobility Reform

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This is a report by the All Party Parliamentary Group for Paediatric Mobility Reform compiled from evidence given by a group of experts over a series of sessions held in Parliament in the autumn of 2010. The evidence given describes the views of those experts on the state of NHS wheelchair provision for children and young people.

While similar issues may persist in the other nations of the UK because of the devolved nature of the NHS the experts were asked to comment specifically on provision in England alone.

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Foreword from Greg Mulholland MP,

Chair of the APPG for Paediatric Mobility Reform



Greg Mulholland MP
Chair of the APPG for Paediatric Mobility Reform

I am delighted to introduce this report from the All Party Parliamentary Group for Paediatric Mobility Reform.

The APPG has been established for two years now, with the kind support of the charity Whizz-Kidz which provides mobility equipment and training to disabled children and young people across the whole of the United Kingdom.

Since then I have met young people, in Leeds and London, who are wheelchair users and seen a 'Wheelchair Skills' scheme established in my constituency. What becomes clearer with each visit, initiative and event is that child mobility is vitally important, and more has to be done to ensure that children across the country have access to the equipment they need.

It is a sad fact that today there are still 70,000 children who have their mobility needs unmet. That is 108 children in each MP's constituency, and although Whizz-Kidz is able to reach 1,000 young people per year, the number continues to rise.

This report seeks to highlight the success of the Whizz-Kidz model for NHS wheelchair services for children and young people. Members of the Parliamentary Group visited their Tower Hamlets service to see the successes of the initiative. In Tower Hamlets there is no waiting list and the equipment provided is appropriate and more sophisticated than is routinely provided by the NHS in other parts of the country. The model also offers a saving of 60% for each wheelchair issued.

So where do we go from here? The Government are currently reviewing how Health, Education, Social Care and Special Educational Needs and Disabilities function, and Sarah Teather has outlined plans to 'join-up' these services. This provides a wonderful opportunity to integrate the 'Tower Hamlets Model' more widely.

The benefits of developing this scheme are not contained to one department; the Department for Education would save money on classroom assistants and providing some specific equipment, such as different height desks, whilst promoting accessible, independent learning.

The heart of this report is about giving all young people the chance to lead a normal life. To give all young people the chance to develop their independence, to get the most out of their education, and the best chance of pursuing rewarding careers. To give all young people the confidence and self belief to lead their everyday lives and do the things that every young person should have the right to do – to play, learn and socialise.

Executive summary

Presentation of evidence to Parliament: Reforming national paediatric wheelchair services

The All Party Parliamentary Group for Paediatric Wheelchair Reform was formed in 2009 to highlight the need for reform of wheelchair services for children and young people. The group is sponsored by the national charity Whizz-Kidz which provides mobility equipment and training to disabled children and young people throughout the UK. Experts providing evidence included paediatricians, physiotherapists, executives and other professionals from the Department of Health, the Care Quality Commission, the NHS and Whizz-Kidz, as well as three young beneficiaries of Whizz-Kidz's services.

The Big Picture

There are currently an estimated 70,000 disabled children and young people in the UK who have unmet mobility needs. To achieve independence, self-sufficiency and, in many cases, basic comfort and health, these children need properly fitted wheelchairs appropriate to their individual needs. Reform of paediatric wheelchair services is absolutely necessary to break the cycle of discomfort, pain, dependence, and the many other disadvantages that disabled children experience as a result of inadequate provision and negatively impacts our society as a whole.

Model of Success: Whizz-Kidz and Tower Hamlets

Whizz-Kidz partnered with the NHS Tower Hamlets to reform the borough's paediatric wheelchair services with resounding success, demonstrating that wheelchair service reform is achievable within budget. As a result of the changes implemented, disabled children and young people in Tower Hamlets now receive better quality wheelchairs, procured at lower costs, with shorter waiting times, higher satisfaction, better mobility and wider benefits. In other words, the reforms have been an unqualified success.

Fundamentals for Success

The fundamental principles underlying Whizz-Kidz's success include providing the right equipment, based on the right assessments, at the right time. This means that children and young people get chairs that are designed to meet their specific clinical and lifestyle needs, as determined by specialised paediatric therapists. They do not receive scaled-down versions of adult chairs. Assessments are holistic and family-orientated, and waiting lists are minimised, sometimes eliminated altogether.

Efficient Procurement Strategy is Essential

To achieve these impressive results, Whizz-Kidz relies on intelligent procurement strategies which enables them to have fast access to consignment stock without maintaining their own expensive warehouses. Whizz-Kidz leverages its therapists' paediatric expertise to plan for predictable equipment specifications and to prevent unnecessary over-specification of equipment, thereby reducing waiting times and minimising cost. Procurement channels are designed to source bespoke children's equipment, and encourage the provision of creative solutions.

Eligibility Criteria

In contrast to the restrictive, disparate and often seemingly arbitrary eligibility criteria in place in areas throughout England, it is Whizz-Kidz's credo that no child or young person is refused equipment if he or she is in need of mobility aid.

Cost is Not Prohibitive

With improved efficiency and by taking a longer-term perspective on cost management, expense will not be prohibitive to instituting dramatic reforms in wheelchair services generally. This was demonstrated convincingly by Whizz-Kidz's transformation of the paediatric wheelchair services in Tower Hamlets.

Recommendations

(1) **Prioritisation:** Ensure that paediatric wheelchair reform is spotlighted and placed very high on the political agenda. Apply political pressure to ensure that reformed paediatric wheelchair services are now a top priority within the wider NHS reform agenda.

(2) **Articulate minimum standards:** Articulate uniform standards which prescribe nationally the level of care that paediatric wheelchair services provide and, very specifically, the outcomes that must be achieved. This specific guidance should be accompanied by follow-up performance monitoring and on-going dialogue with providers to ensure standards are maintained.

(3) **Initial investment:** Although efficiency, procurement strategy and a sensible long-term approach to cost control are very effective in making wheelchair reform achievable, there are some areas that will need additional funds to institute these necessary changes. For all the reasons outlined in this report, initial investment in such improvements will prevent human and societal costs down the road and, ultimately, lead to wider savings in health and other public services.

(4) **Joint working across local and national government departments:** Consideration of collective costs of inadequate provision – across government departments, the NHS and local authority budgets – highlights the need for effective leadership and coordinated action to reform wheelchair services and achieve wider benefits to society, the government as a whole and better outcomes for disabled children and young people.

(5) **Roll out of proven service models:** The Department of Health must work closely with those organisations already leading the way in effective procurement, assessment and delivery of wheelchairs to develop an implementation plan that delivers improvements to services across the country and ensure that all disabled children and young people have access to the right equipment at the right time.

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I. The big picture

Disabled people represent one fifth of the working age population of the UK, but are far more likely to be out of work, to lack skills and to live in poverty than the population as a whole. Improving skills and increasing employment rates for disabled people matters not just for equality and social justice, but also for national prosperity. Raising the employment rate of disabled people to the national average would boost the UK economy by £13 billion, the equivalent of six months' economic growth. (Social Market Foundation Report, June 2007). Critically, success relies on raising the aspirations of disabled people and increasing their opportunities, as well as improving society's attitudes towards disabled people and raising its expectations of them.

It is crucial that this process starts in childhood, and the earlier the better. The sooner disabled children are allowed to achieve age-appropriate independence, the better they can develop the skills and confidence on which they will rely throughout their lives. For the mobility-impaired child, having the right wheelchair to suit his or her needs is fundamental to being independent. Furthermore, disabled children who are mobile, independent and confident in childhood leave an impression on their peers as being active and capable; positive perceptions which will stick with those other children throughout their adult lives. It is imperative that reform of wheelchair services for children and young people be prioritised to break the cycle of discomfort, pain, dependence, and the many other disadvantages that disabled children experience – and negatively impacts on our society as a whole – as a result of inadequate provision.

II. Model for success: Whizz-Kidz and Tower Hamlets

Throughout the rest of this report, evidence will be presented highlighting how critically important it is to reform wheelchair services. Expert witnesses will show that it is irrefutable that mobility-impaired children need to be provided with the right equipment, based on the right assessments, at the right time. The necessity of providing specialised paediatric services, instituting efficient procurement strategies, standardising eligibility criteria and focusing on outcomes rather than cost will be made clear. First, however, we need to believe that these reforms are achievable. The partnership between Whizz-Kidz and the Tower Hamlets Primary Care Trust provides us with the model for success.

About Tower Hamlets

The inner-city demographics of Tower Hamlets make this borough particularly convincing as a success story. According to the Office for National Statistics, *Labour Force Survey* (ONS, 2007), disabled children are 50% more likely to be born in an inner-city area than their non-disabled peers. Disabled people are also far less likely to be skilled; they are half as likely to have a degree and twice as likely to have no qualifications at all. They are similarly less likely to be employed; only 50% are in work, compared to 75% of the population as a whole. Consequently, Tower Hamlets' high unemployment rates and large population of disadvantaged minorities mean that its wheelchair services had an above-average caseload from the outset of the project. It was thus a particularly challenging place to make reform a reality.

Partnership with Whizz-Kidz

In 2007, NHS Tower Hamlets formed a partnership with Whizz-Kidz to deliver wheelchair services to children and young people at the Mile End Hospital. The goal of the partnership was to provide a high standard of service in line with Whizz-Kidz practices. These high standards include providing the right equipment to meet the children and young people's specific needs, providing specialised assessments by paediatric therapists, reducing or eliminating waiting times, and having a flexible approach

to the application of eligibility requirements; it is the Whizz-Kidz credo that no child or young person is refused equipment if he or she is in need of mobility aid. In 2008, Whizz-Kidz became the lead provider for the paediatric wheelchair service at NHS Tower Hamlets.

Accolades

Within the first year, Whizz-Kidz worked with the established service to deliver equipment to over 100 children and young people who had previously been on the waiting list. In 2008, the service was awarded the Health and Social Care Award for Dignity in Care by the Social Care Institute for Excellence for the "first initiative of its kind to systematically pool resources and expertise of the statutory and voluntary sector to provide an integrated service."

The same year, Rt Hon Ed Balls MP and Rt Hon Alan Johnson MP, as Secretary of State for Children, Schools and Family and Secretary of State for Health respectively, visited the wheelchair services to see the success for themselves.

In 2009, the Department of Health and the Department for Children, Schools and Families published the Child Health Strategy.

In this publication, NHS Tower Hamlets paediatric wheelchair service was held up as good practice, and it was recommended that other primary care trusts consider adopting the same model.

In 2009, Andrew Lansley, the Shadow Health Secretary at the time, visited the Tower Hamlets wheelchair service and asked Ruth Owen, the CEO of Whizz-Kidz, to present on the future of wheelchair services to the Conservative Party Conference. When David Cameron presented on the future of the NHS, he proclaimed that "the charity Whizz-Kidz is a good example of how a genuine partnership approach can work."

Success

Since 2007, Whizz-Kidz has virtually eradicated the waiting list. The majority of new referrals are provided with an appointment within two weeks, and many

take their new equipment home on the day of their first appointment, a process which is aptly named 'child in a chair in a day'. Whizz-Kidz has earned 100% satisfaction rates, which is not only indicative of success, but has saved NHS Tower Hamlets from defending complaints which cost in the region of £1,000 per complaint. Whizz-Kidz has succeeded in focusing on early provision, helping give powered mobility to children as young as two years old. The success of the partnership and the work of Whizz-Kidz have resulted in over 400 children and young people receiving the equipment and care that they needed.

To achieve this success, Whizz-Kidz formed strategic alliances with corporate partners to ensure an efficient and effective service. Tesco PLC introduced Whizz-Kidz to procurement specialists who have helped the charity access bespoke mobility equipment more quickly and at lower prices. Accenture (UK) Ltd introduced process consultants who helped Whizz-Kidz develop lean processes enabling them to provide many children with equipment on the same day as their assessment. In the future, Whizz-Kidz hopes that up to 70% of its beneficiaries will go home from their assessments with their wheelchairs.

In addition to delivering equipment, Whizz-Kidz also offers advice, training courses and social opportunities for the children and young people they serve. All beneficiaries are offered the opportunity to become ambassadors for Whizz-Kidz. As ambassadors, they can play an active role in the charity's work, attend their local ambassador club meetings, and get the chance to take part in training, work placement opportunities and events which help them gain essential life skills – all while making friends and having fun. As a result, children and young people are developing confidence, independence and a sense of empowerment, whilst also enjoying being directly involved in the charity's work.

In 2010, Whizz-Kidz commissioned a report from leading health economists Frontier Economics to measure the progress achieved in Tower Hamlets since 2007.

The report concluded that as a result of the changes, the population of Tower Hamlets now receives better quality wheelchairs, at lower costs, with shorter waiting times, higher satisfaction, better mobility and wider benefits. In other words, it has been an unqualified success.

More specifically, in compiling the report, Frontier Economics found that under the new scheme, the cost per wheelchair is on average £1,100, in contrast to the former £2,700 price tag through 'business as usual' methods. Whizz-Kidz has thus succeeded in delivering the right wheelchairs, faster and more easily, with a cost savings of 60%.

The report also cited significant, less quantifiable benefits, including the wider healthcare savings of preventing future clinical complications by providing equipment promptly. Additionally, it

acknowledged the improved quality of life for carers, and the fact that faster access to the right equipment frees up time for family members to accept more paying work and to spend more time with other members of their families, ultimately improving the quality of life for many. In reaching these conclusions, Frontier Economics emphasised that it nevertheless had adopted a conservative approach, and did not take into account the improved education and employment opportunities for the beneficiaries, which are likely.

If such unmitigated success can be achieved in Tower Hamlets, it can be achieved in any other wheelchair service in the country. The argument for reform is highly compelling, and is further promoted in the following examination of the fundamental principles and strategies that form the basis of Whizz-Kidz's success.

"Since Whizz-Kidz first partnered with Tower Hamlets, the organisation has seen approximately 400 children and young people, and provided access to appropriate mobility equipment and also training. Assessment has been very holistic, looking at medical needs, but also social needs and training needs, with very much a focus on ensuring that children and young people are able to realise their potential despite their disability. I am very pleased to say that from a quality perspective, the waiting times have been reduced substantially and, in fact, there are now no waiting times in Tower Hamlets. There is very high satisfaction from the children and young people and their families. Having witnessed numerous children being assessed and receiving their wheelchairs, and just seeing the independence that gives those children, and hearing their own personal testament is amazing and I very much see my role as supporting Whizz-Kidz in brokering their partnerships with the NHS."

Alwen Williams,

Chief Executive, London and City Alliance NHS Formerly the CEO of NHS Tower Hamlets

III. Fundamentals for success:

The right equipment, the right assessments, and the right timing

“On a biological level, getting the right chair is critical if you are going to make sure that a person’s physical development is not hampered. Depending on the disability, you can have, as a result of not being in the right chair at the right time, deformities develop which inhibit that person’s ability to do everyday activities and ultimately look after themselves, go to work and gain an education.”

Carol Squire,

Joint Head of Integrated Occupational Therapy & Community Equipment Services, NHS Tower Hamlets

The Right Equipment

Each child or young person with impaired mobility needs appropriate equipment fitted to his or her specific needs. With the right equipment, mobility-impaired children can lead lives on a par with their peers. Children can play, learn, and develop physically and emotionally. Young people can socialise with their friends, go to university and join the work force. They can achieve freedom from their parents and carers, develop their own personalities, participate in society, contribute and take charge of their own lives.

“I always say that my wheelchair is my shoes. At the end of the day, it’s a pair of shoes to me and it gives me the ability to lead an independent life. You wouldn’t think of sending a child to school without any shoes in this country, and if you did you would be hauled up for negligence... I think there is nothing more empowering than to get your first taste of freedom... you don’t lose that feeling of making your own choices, your own friendship circles, the fact that you just want to be naughty for that day or have a strop or go to your bedroom and have a sulk away from your parents.”

Ruth Owen,

Chief Executive of Whizz-Kidz

It is vitally important that children have chairs that are designed to suit their needs, rather than scaled-down versions of adult chairs. For a chair to provide real mobility, by definition, the child needs to be able to use it to move around. For many children

this means having a powered chair. On the whole, it is very difficult for children to access powered wheelchairs through the NHS.

For some children, however, the best option is an agile, manual wheelchair that they can operate under their own steam, maximising their physical capabilities. Heavy adult equipment can entirely subvert the potential benefits of a manual chair. Lightweight manual chairs can weigh as little as 4kg and still provide all the requisite postural support. These chairs can be specially fitted with ‘eMotion wheels’ which enable the user to navigate hills, sharp ramps and steep inclines. eMotion wheels provide power-assistive technology to propel the chair through places that might not otherwise have been accessible. As a result, children can take advantage of their existing physical abilities without hindering their ability to get around comfortably and efficiently.

Powered chairs and specially-fitted lightweight manual chairs are examples of solutions that can meet the specific needs of different young people. These young people’s disabilities do not need to prevent them from living their lives very much like their peers do; they just need the correct equipment to do so.

Potential clinical problems

The clinical problems caused by incorrect or ill-fitting wheelchairs, particularly by scaled-down adult chairs, include a variety of injuries, pressure sores, septicaemia, rotator cuff tendinopathy (degeneration of the tendons around the shoulder), dislocated hips, scoliosis, deformities, hospitalisation

and surgery. Sometimes children’s wheelchairs cause them so much pain or spasm that they are only able to sit in them for very short periods.

“Some of the equipment the NHS is providing is actually detrimental to young people’s health. Basic things like where wheels are positioned in relation to the shoulder – so they are actually providing equipment which is building in the need for surgery later.”

Ian Legrand,

Strategic Service Advisor, Whizz-Kidz

“I see, on average, three or four new patients a week with unmanaged pain and discomfort from badly-adjusted equipment. I see a further two or three, on average, follow-up young people who have on-going issues needing to be addressed. This brings you to about six per week. However, if you include the spinal and orthopaedic service as well, we are seeing at least double that number.”

Charlie Fairhurst,

Consultant Paediatrician for Chailey Services, Sussex; Consultant of Paediatric Neurodisability, Evelina Children’s Hospital, St. Thomas’, London; Clinical Governance Lead for the British Academy for Childhood Disability

Providing the correct equipment, fitted properly, can prevent these problems entirely. Researchers support this view, including Boninger, et al (2000), Samuelson, et al (2004) and Mulroy, et al (2005). The Spinal Cord Rehabilitation Unit has concluded that:

There is level 4 evidence that more forward position of the rear wheel improves push rim biomechanics, shoulder joint forces, push frequency and stroke angle. Manual wheelchairs with adjustable axle position appear to improve wheelchair propulsion and reduce the risk of upper extremity injury.

The right seating is of paramount importance to someone who must sit in a chair for more than 12 hours per day. According to May, et al (2004), prescribing the correct seating facilitates

Dominic

"the management of abnormal tone, accommodation or prevention of deformity, improvement or maintenance of functional skills, accommodation for impaired sensation and provision of comfort."

The right equipment can prevent discomfort, pain and other grave clinical problems experienced by too many children.

Potential developmental problems

Having the wrong chair can cause a child a myriad of developmental problems as well. Children who are not allowed age-appropriate independence and who are simply pushed around by their carers, left out of ordinary childhood interaction, can develop learned helplessness. Playing is a crucial developmental process; a child who is trapped immobile, or whose hands are not free, cannot play like other children. When a child is reliant on being pushed around, there is very little chance for his or her personality to become the dominant feature in interactions; interactions will always be dominated instead by the presence of the person pushing the chair. From a purely social perspective, it is intuitive that a young person cannot socialise with peers on an equal level if that young person has no autonomy or privacy.

Having the correct equipment can also be important for the development of communication.

"[I want to stress] the importance of wheelchair provision in communication and cognitive development because my earliest exposure to wheelchair services is actually through developing augmentative communication devices for children, that is speech outlook devices. More often than not we never got as far as being able to advise on what kind of communication aid that child would need. They wouldn't actually have a wheelchair to fix it on to, so they weren't in a position where they could use it. So, those children were being deprived not just of their mobility, but also of the ability to communicate."

Hilary Cass,

Paediatric Neurodisability Consultant Guy's and St Thomas' NHS Foundation Trust; Trustee Board Member, Whizz-Kidz

A child who is unable to communicate and unable to develop properly is inevitably going to have a very difficult time succeeding in school, having relationships, going to university, finding work, and leading a happy and productive life.

The Right Assessment

Central to providing the right equipment is correctly assessing the needs. Specialised paediatric therapists (who may be either occupational therapists or physiotherapists by background) are best able to recognise the needs of each child and prescribe the best equipment accordingly.

Specialised assessments for children

It is important to remember that paediatric assessments are fundamentally different to adult assessments. Children are not only smaller, but they grow and develop, have different lifestyles, different vulnerabilities, different activities, different capabilities and different limitations.

"We need a very specific compare and contrast regarding what is needed for children and what is needed for adults, and what is done for adults would not necessarily work for children, so we need to look at this population differently."

Hilary Cass,

Paediatric Neurodisability Consultant Guy's and St Thomas' NHS Foundation Trust

"Some primary care trusts don't even have a paediatric therapist, and many primary care trusts throughout the UK provide predominantly adult wheelchairs for adult services, and children are left on the side. You don't need hundreds of wheelchairs but you do need more than one."

Charlie Fairhurst,

Consultant Paediatrician for Chailey Services, Sussex



Dominic is four years old and lives at home with his mum. Dominic has a neuromuscular disorder and by the age of three years he was still unable to crawl, stand, or walk due to muscle weakness. As he passed the stages where children achieve these different milestones, he had remained very dependent on his mum. His mum said that he was so reliant on her that he was 'scared to do anything without help'. He wouldn't even ask for toys, playing only with whatever was next to him and within reach.

Concerned that Dominic was not achieving crucial stages in his development, his mum approached the local wheelchair service only to be told that, at three years of age, he was too young to qualify for equipment.

After getting in touch with Whizz-Kidz, Dominic now has a powered wheelchair with dual controls. The dual controls mean that he can practice and build confidence getting about in his chair while his mum looks on knowing she can step in and help if he needs it. His mum now says he's unrecognisable as he chases his brother and sister around the park.

Holistic, friendly approach

The therapists at Whizz-Kidz provide holistic assessments which take into consideration many elements, including clinical needs, physical abilities, and characteristics of the schools, homes and communities, as well as individual preferences.

"Things that families repeatedly and consistently say are of constant concern to them, you won't be surprised to hear, include access to the right support at the right time. It is about timeliness, it is that pathways are managed, it is that families are the priority and are prioritised within the system. It is that they have information that they need, and that they also feel able to influence and make choices regarding their concerns. Families need to feel included, and particularly need to feel that they have support to access the right wheelchairs."

Karen Naya,
Development Manager, Care Quality Commission

At Whizz-Kidz, dedicated paediatric therapists provide personalised, attentive services so that a given child sees the same therapist each session, and the family can develop a relationship with that therapist.

Children and young people are often more sensitive to their environments. To promote optimal communication, it is important for them to be in an environment that is friendly and comfortable, in which they can feel relaxed about attending appointments and confident about expressing their needs. A child is in the best position to explain when a piece of equipment does not feel quite right, and it is vital to success that such feedback is heard, and that the child feels empowered in his or her circumstances. Having a one-on-one relationship with the therapist makes it easier.

Unlike most adults, young people have parents and families who are inextricably involved in their choices and in their care; it is important that parents and family members also feel that they can raise concerns and be a part of the dialogue.

The child-parent dynamic is unique to paediatric cases, and is therefore a dynamic that Whizz-Kidz has experience managing. Whizz-Kidz believes in a focus on the young person.

"There can be conflicts because we and the child and the young person want to be mobile, and they want to go down to the park with their mates, but mum wants them to sit in the buggy because it looks normal."

Ian Legrand,
Strategic Service Advisor, Whizz-Kidz

"[In the NHS services], I think you're not always listened to, I think it's very slow, I think it doesn't always focus on the child and the young person, it tends to be focused quite on the family and the parent, and I think that one of the things we do as an organisation is very much focus on the young person."

Ruth Owen,
Chief Executive for Whizz-Kidz

Without holistic, specialised, family-friendly and child-friendly personal assessments, it would be impossible to guarantee that any piece of equipment, regardless of quality, would be the best equipment for that child.

The Right Timing

Waiting lists

While the right assessment can determine what the right equipment is for a particular young person, if the waiting list for the child is long, neither the right assessment nor the right equipment will do any good. Waiting lists, sometimes shockingly lengthy, are practically endemic to NHS wheelchair services for children.

"I have had experiences in the past where, in the NHS, children have been waiting 12-13 months for an initial assessment to be seen and it is roughly the same time again that equipment can be provided for them, so obviously you've got all sorts of difficulties around whether the assessment is still relevant by the time the equipment is being received."

Kate Hallet,
Senior Mobility Therapist, Whizz-Kidz

When children need to wait for over a year after their initial assessment to receive their equipment, as is often the case, they are likely to have outgrown the wheelchair by the time they receive it. What once may have been the right chair becomes the wrong chair, with all the attendant complications. Of course, this means wasting money on the wrong chair, causing pain and discomfort for the child, risking future surgeries and hospitalisation, and causing the child to miss out on life in the interim. Sometimes the young person waits more than a year just for the initial assessment; this too means that he or she is foregoing critical care.

"In 2007, some very long waiting times, including a four-year waiting time, were quoted for powered wheelchairs, citing lack of funding."

Dr. Sheila Shribman, National Clinical Director for Children, Young People and Maternity Services; Department of Health, Partnerships for Children, Family and Maternity Division

"The net result I think is that children wait too long for equipment that is not as appropriate as it could be, thereby limiting their own independence and their own development."

John Cowman, Director of Community Services Waltham Forest at ONEL CS; Director of Business Development for ONEL CS at NHS Havering

Whizz-Kidz has already proven through its work with Tower Hamlets and other primary care trusts that these waiting times can be drastically reduced or eliminated completely.

Whizz-Kidz provides us with models of these fundamentals of success. Providing the right equipment, based on the right assessments, at the right time to mobility-impaired children and young people is an achievable vision. For thousands and thousands of children, and the many people in their lives, addressing the existing problems in wheelchair services would make an enormous difference.

IV. Procurement strategy

How is Whizz-Kidz able to do such an effective job? Procurement strategy is at the core. The importance of a streamlined, outcome-driven procurement strategy cannot be overstated. Through corporate partnerships with Tesco and Accenture, Whizz-Kidz has worked with procurement experts and process consultants to develop an exceptionally effective procurement strategy.

Current NHS practices provide an illustrative comparison. The NHS uses the same suppliers that it has been using for many years. It engages with these suppliers using framework agreements, as opposed to negotiating actively with suppliers and engendering competition. As a result, the NHS ends up purchasing the same equipment year after year, and does so at inflated prices. Whizz-Kidz, on the other hand, can spend the same amount of money but receive much more sophisticated equipment, equipment which is suited specifically for the young person who needs it.

"There is a lot of competition around. Having had a short exposure to Whizz-Kidz, we can see what we are getting for our buck. If better procurement is going to lead to good quality for the price, and if reducing waiting times means you do not invest in a chair which the child would have outgrown, this would be a much more effective commission of resource."

Hilary Cass,

Paediatric Neurodisability Consultant Guy's and St Thomas' NHS Foundation Trust

How does Whizz-Kidz's procurement strategy achieve these results?

No warehouses, yet fast access to stock

Whizz-Kidz works with manufacturers, negotiating for consignment stock in exchange for providing substantial business. In this way, Whizz-Kidz does not pay to hold the stock, but can access it immediately.

"When we talk about Child in a Chair in a Day, the first thing the NHS will say to us is, 'How big is your warehouse?' Well, we haven't got a warehouse – we are actually quite smart about what we do. A lot of back work went into this, but it means that we are getting products at NHS prices or lower, that we are using enhanced products, and that we are getting that product when we need it."

Ian Legrand,

Strategic Service Advisor, Whizz-Kidz

Having access to sophisticated, bespoke equipment at low cost, with reduced or no waiting times, makes this facet of Whizz-Kidz's procurement strategy integral to the objectives of providing the right equipment, based on the right assessment, at the right time.

Planning for predictable equipment specifications

Whizz-Kidz creates a matrix of products, a formula which enables them to prepare for foreseeable equipment needs. Before a child comes in for an assessment, his or her information will be used to determine which product area will likely be in demand. A child under 5, for example, likely needs a powered chair with special dual controls to enable the parent or carer to retain full control while the child gains confidence and gets used to navigation. Whizz-Kidz therapists have this information in advance, and can have a chair with dual controls accessible by the time the family comes in for the assessment. Then during the assessment, the equipment is adjusted to fit the child. This procedure allows many children to leave their initial assessments with their new equipment, fulfilling the Whizz-Kidz vision of 'Child in a Chair in a Day'.

Children and young people receiving dedicated services

Children and young people at Whizz-Kidz receive specialised attention from paediatric therapists. These therapists are experts at understanding and predicting the specific needs of young disabled people and

Samuel



Samuel is 13 years old and lives at home with his parents and brother in Oxfordshire. Samuel has Muscular Dystrophy which means he can't walk very far or propel himself in a manual wheelchair for long distances.

Samuel had a manual wheelchair but due to his muscle weakness he was reliant on others to push him around. He wanted the freedom to go out on his own and visit his friends' houses.

His own PCT would only offer him a manual chair and not a powered one, so Samuel's parents came to Whizz-Kidz. After seeing one of Whizz-Kidz's specialist therapists a brand new powered wheelchair was ordered for him. Samuel has now been able to join the scouts and take part in a range of other activities.

"Having the powered wheelchair has given Samuel great independence. He goes into town with his mates, visits the cinema and is able to attend scouts and other clubs. He uses the standing mode when he is at school to stretch his legs and participate in badminton and other sport. Basically it has given him a new lease of life and he loves using it."

Samuel's Mum

children, and can determine and articulate equipment specifications accordingly. The procurement channels are designed to meet the equipment needs of young wheelchair users, with a heavy focus on getting the right mix of equipment which can be configured in a way that allows therapists to prescribe for the full range of mobility needs.

Motivating manufacturers to prioritise wheelchair users

Manufacturers who are encouraged to view disabled children and young people as their customers are inspired to work hard to provide them with the best equipment to suit their changing needs. In contrast, manufacturers who view the wheelchair services as their customers will respond mechanically to the repetitive, high volume specifications those services request.

“One of the things we wanted to do was to improve our supply chain, and actually our wheelchair provision is more consumer-led than it has ever been... What we want to do is to make sure that the manufacturer sees the customer as the person who is important to them. The NHS spends a lot of money, but the manufacturers do not have to work very hard.”

Ruth Owen,
Chief Executive of Whizz-Kidz

Preventing over-specification of equipment

At some charities where grants provide funding for equipment, the relevant user assessment is actually provided through a commercial company. In these instances, it is not unusual for a wheelchair to be over-specification, in other words, it would have more ‘bells and whistles’ than that particular user needs.

“We have had to step in when equipment has been provided that has not been fit for purpose. A piece of equipment that costs £20,000 could literally be replaced with something much more appropriate for as little as £2,000.”

Ruth Owen,
Chief Executive of Whizz-Kidz

It is important to ensure that the supplier is complying with the assessment specifications to ensure that money is not wasted purchasing unnecessary equipment, that money will not later be wasted repairing unnecessarily sophisticated equipment, and to ensure that disabled young people are provided with equipment which maximises their abilities and enables them to exercise their full range. Over-specification equipment can rob them of the opportunity to live to the boundaries of their physical potential.

“When the NHS sees a product, they want to know if it is compatible with what they have always had before, so product development has not really moved on. The NHS has actually suppressed innovation in the industry because they just keep buying the same old stock.”

Ian Legrand,
Strategic Service Advisor, Whizz-Kidz

V. Procurement challenges

Children lumped in with adults

While Whizz-Kidz provides specialised services only for children and young people, most other services combine children and adult services, with a tendency to focus very heavily on the adult service. Procurement processes at these services, therefore, are designed mostly for the acquisition of high volume adult chairs, leaving children to endure scaled-down versions inadequate to their needs. Children's chairs require creative, proactive procurement processes.

"The funding of complex chairs is put under more pressure by the merging in a single annual budget of both high volume (usually adult) and bespoke chairs (more often children's). Without contingency planning for complete needs, a shared budget may be spent entirely on standard, relatively cheap, adult wheelchairs."

Professor Trish Morris-Thompson,
Chief Nurse, NHS London

Fragmentation of wheelchair services nationally

Having 151 different wheelchair services with 151 different people procuring equipment with 151 different budgets is not conducive to efficiency.

"There needs to be some kind of scale. There needs to be local access, but for the services around paediatric and young people there is a limited amount of knowledge; you need to stop diluting that across 151 services. Most services are around 5,000 wheelchair users, and in London around 3,000. The critical mass would probably be about 12,000 – 14,000; that would start giving you the scale you need."

Ian Legrand,
Strategic Service Advisor, Whizz-Kidz

Lack of prioritisation

Paediatric wheelchair services have not been high on the agendas of many chief executives and commissioners. It is not considered core business; it is such a small piece of the pie that it does not get the focus and attention of national targets. Given the gravity of the circumstances of the 70,000 children and young people whose needs are being neglected, and in light of the proven achievability of dramatic improvements, much more political pressure must be applied to get paediatric mobility high on the political agenda. Whizz-Kidz has been actively lobbying to do just that.

"At the moment, lots of people are making decisions, services are too small and they are putting a lot of cost into the service. If you take East London where we are working, you have got three managers and three sets of stock. We have done amply with one service providing service to three boroughs. That would loosen up a lot of investment."

Ian Legrand,
Strategic Service Advisor, Whizz-Kidz

VI. Eligibility criteria

The expert witnesses have unanimously discredited the eligibility criteria currently in use disparately throughout the country, criteria which categorically deny thousands of children and young people access to the equipment and services they need. There are currently approximately 70,000 children and young people in need. That means that there are 70,000 mobility-impaired children and young people who are either using the wrong equipment for them, or who have not been prescribed any equipment, due to categorical restrictions. The expert witnesses adamantly agreed that such restrictions were unnecessary, unreasonable and counter-productive from every perspective, including from a cost-saving perspective.

In Tower Hamlets, in contrast, and nationally through Whizz-Kidz, the eligibility criteria are such that no child or young person is refused equipment if he or she is in need of mobility aid. For all 151 services throughout England, this is an achievable objective.

Failures of the Current Eligibility Criteria

As currently applied, eligibility criteria set obstacles for mobility-impaired children and young people, rather than facilitating creative solutions. The criteria are used to exclude children from receiving services, instead of helping children find the right services for them.

When rigid eligibility criteria are in place, the assessment of the child's needs is taken out of the hands of the expert therapist, and instead becomes a blind cost control measure. The results can be devastating.

Age-based exclusions

In many areas, the eligibility criteria prescribe strict age limitations. These limits can vary significantly from service to service.

Denying young children powered mobility

In some areas, powered mobility is denied to any child under the age of 10 by their local eligibility criteria, no matter what the clinical diagnosis. This means that for the independence to get around the house, to go to school, to play outside, to play with

friends, to explore, and to learn, and to develop as a child and as an individual and as a person, this child has to wait ten years.

"If you have to wait 10 years for a wheelchair, that is your childhood over. I think that is a shocking indictment of services in this country."

Ruth Owen,
Chief Executive of Whizz-Kidz

By the age of 10, a disabled child denied necessary equipment will often have developed a range of problems otherwise potentially avoidable, including clinical, developmental, social and mental health issues. Nevertheless, refusal to provide critical powered mobility is pandemic in the UK. In 2007, the Care Services Improvement Partnership reported that of 12,164 wheelchairs issued to children in 2006/2007, 98% were manual wheelchairs. The report also asserted that many of the chairs issued were scaled-down adult chairs that did not meet the users' needs, or allow independent user activity.

Undermining age-appropriate independence; risking learned helplessness

In some areas, children under 5 are not provided with wheelchairs at all, but are expected to stay in their buggies to be pushed around by their parents or carers. The NHS will often say it is out of concern for the child getting hurt using a powered chair, but this is inconsistent with the fundamental purpose of providing children with mobility: to achieve age-appropriate independence while meeting clinical needs.

"You wouldn't send a five-year old down the shops on their own anyway, so what we are saying is it needs to be appropriate. All the evidence says that the earlier you can get children mobile, as close as you can to their peers, then the better the long-term outcomes."

Ian Legrand,
Strategic Service Advisor, Whizz-Kidz

Research shows that children who are denied early provision of appropriate mobility equipment learn to become helpless.

'Learned helplessness' describes the psychological condition of those who suffer extensive uncontrollable events, who then consequently maintain the false belief that they have no power to change or improve their circumstances. As a result, they give up hope of gaining respect or advancement, and stop trying. They become helpless.

Young children pushed around in buggies while their peers play and interact on the playground will see their young lives as out of their own control, literally pushed around. These children quickly believe they have no power over themselves, and that sense of disempowerment stays with them.

Not only do buggies prevent a child from developing, but they do not provide proper postural support. Buggies were not designed for children to sit in for endless hours, day after day. In this sense, buggies are not safer for young children than appropriate equipment, contrary to what is often asserted by some NHS services.

"I was surprised about how quickly by the age of 4 or 5 kids can have established learned helplessness, whereas if you get them mobile, even in the case of 13 month-old kids mobile in powered wheelchairs, so that they are going to nursery and mixing with their peer group, then they are just a kid in a wheelchair....Get kids mobile, get them into school, get them to college, get them to be as independent as possible."

Ian Legrand, Strategic Service Advisor, Whizz-Kidz

"There is one young lad I saw who was on frequent painkillers because of the posture he was in, because all he needed was what we call a tilt-in space chair and, by providing that, was able to shift his own position, and he was comfortable. He could come off painkillers. Now, surely, that makes economic sense, as he would have needed further surgery."

Judith Davis, Head of Clinical and Regional Services, Whizz-Kidz

"Being able to provide children with the equipment at the right time in their lives to enable them to be able to develop

as their peers would develop is absolutely crucial. [Not just with respect to] learned helplessness, but also just the way in which the child develops and in which he or she explores the environment. There is going to be so much learning development that child is not going to be able to take on board.

When you are looking at things like the seating on wheelchairs, special seating, if you delay providing that, you are going to have long-term repercussions in terms of spinal deformity of children, which is going to lead to surgeries and all sorts of problems later on down the line. Again, apart from the personal discomfort and pain, you have also got the cost implications of somebody going through spinal surgery at the age of 11 or 12 years old, which could be prevented if they were given the right equipment at the right age."

Kate Hallett,
Senior Mobility Therapist, Whizz-Kidz

Excluding other children categorically
Eligibility criteria are often used to exclude children and young people from wheelchair services based on the category of their specific disabilities, instead of determining on a case-by-case basis what the best options are for the child according to his or her individual and clinical needs. These criteria simply do not take into account that these children's disabilities often do not prevent them from needing or benefiting from powered mobility.

Children with visual impairments
Visually-impaired people who can walk are able to learn to navigate their environments very well because they become familiar with those environments. It does not make sense to assume that visually and mobility-impaired people are any different, nor should the mobility-impaired be deprived of this capability. That would be like saying a blind child should not walk.

"The NHS have eligibility criteria and [people with visual impairment] have to pass a sight test to ensure they can drive a powered chair safely, but we have found that because when people are in their own environment, they know their environment very well, they can actually be independent

within their environment by using a powered chair, but because they cannot pass that eye test within the NHS, then they are not eligible to have it."

Judith Davis,
Head of Clinical and Regional Services, Whizz-Kidz

Children with learning disabilities
Similarly, for learning-disabled children and young people, powered wheelchairs can be useful and necessary tools. A learning disability does not categorically render a child unable to use a powered chair, and such a disability should not be used as a cost control measure at great cost to the child.

"The NHS has certainly shied away from providing children with learning difficulties with powered wheelchairs. Now, if you have got a child who has learning difficulties who can walk, you don't sit them in a corner and say, 'You sit there because you have learning difficulties.' You actually manage the environment, and it should be no different for a child in a powered wheelchair – you manage the environment. Judith [Davis] and Kate [Hallett] have done a lot of work in schools, and training, and the outcomes have been exceptional."

Ian Legrand,
Strategic Service Advisor, Whizz-Kidz

Children with some mobility
Many children and young people are denied the appropriate equipment because they have some mobility.

"A teenager who could potentially maybe struggle to walk across this room would not be entitled to powered mobility outside. But if they want to become an active part of their community and go out with their mates, then actually they need powered chairs. Just because they can struggle across a room means they don't get a chair."

Judith Davis,
Head of Clinical and Regional Services, Whizz-Kidz



Lisa is four years old and lives at home with her parents in Oxfordshire. Lisa has been diagnosed with Type 2 spinal muscular atrophy. Spinal muscular atrophy is typified by severe muscle weakness and can lead to muscle wastage. As a result of this Lisa cannot walk or stand on her own and requires adult help to move even the shortest of distances. Unfortunately, Lisa was not eligible for a powered chair through her local PCT as she was so young.

Lisa enjoys exploring her environment and also likes to be outdoors as much as possible. As early as 2 years of age Lisa began to crave independent movement. Unfortunately, her condition meant that she could only shuffle along the floor, and sit with full support from both of her arms. Her parents began to worry about Lisa developing any learned helplessness and wanted to give her the chance to move around on her own like other children.

Whizz-Kidz was able to provide Lisa with a powered wheelchair suitable for use indoors and outdoors. This chair gives Lisa excellent and easy mobility, and even at such a young age she has been able to master the controls with ease.

Josh



Josh is 9 years old and lives at home in a specially adapted bungalow with his mum, dad and sister in Devon. Josh has Type 2 spinal muscular atrophy which means he has ongoing back problems and has to stay in a wheelchair.

As Josh was growing up it was evident that he would need a powered wheelchair. Unfortunately, the local PCT did not issue powered wheelchairs to children under 5 years old. When Josh was 2 his family applied to Whizz-Kidz for help getting him a powered wheelchair. Whizz-Kidz issued Josh with a powered wheelchair.

Josh says without his chair he would be unable to chase his sister and their dog around outside and his teacher would have to push him everywhere in school.

When Josh reached the age of 8 he was growing out of his wheelchair. One of Whizz-Kidz specialist therapists assessed Josh and decided another powered wheelchair was needed. This one came with the optional attachment of a football bumper enabling Josh to play football with his family and friends.

"It was tick boxes. Can she use her arms? Yes. Her legs? No. So have the manual wheelchair, as this will give her independence. But it didn't give me independence as I was being pushed around."

Arunima Mirsa,

23 year-old; lawyer; graduate of Cambridge University and beneficiary of Whizz-Kidz since age 14

The Postcode Lottery

Across the 151 different wheelchair services, there are no coherent standards outlining what equipment and services will be provided to whom. From service to service, there is wide variability in what is provided; some children have their needs met adequately, some have their needs met partially and some do not have their needs met at all. This patchiness means there is a postcode lottery which not only seems patently unfair, but highlights the fact that the current system is not consistently needs-driven. If children and young people are to be treated based on their needs, there must be standards that are consistent for all families, and these standards must be based on outcomes, not arbitrary rules.

"It does not seem the budget is transparent for patients and families so it is very difficult, for example, if you have a school with 8 different wheelchair services feeding into it. One family can say that their child is more likely to receive a better wheelchair, while another child in the same classroom is receiving a different service and the quality is not so good."

Charlie Fairhurst,

Consultant Paediatrician for Chailey Services, Sussex

VII. Cost is not prohibitive: why?

Efficiency can be vastly improved

High management and cost overheads are typical within the NHS wheelchair services. Figures were cited for one primary care trust which had a budget of £450k, of which only £50k went to purchasing equipment, and the experts commented that this breakdown was very average.

Efficiency can be vastly improved by more effective commissioning, looking at how services are managed, and focusing on outcomes.

"I think there is a lot of lazy commissioning. No one has spent the time seeing what is actually needed and focused on outcomes rather than cost."

Ian Legrand, Strategic Service Advisor, Whizz-Kidz

"A lot of it is about performance monitoring, management and checking that the providers who are commissioned are delivering what is stated in the contract. There's something about contracting and making sure we've got the right contract in place and making sure that what you are commissioning and contracting meets any needs as identified in the needs assessment, and where providers are not performing to specifications – also appropriate performance managing if necessary, decommissioning and tendering if appropriate."

David Hill,
Commissioning Manager,
NHS Tower Hamlets

"How much finance you have comes from how well you manage the service in the first place."

David Hill,
Commissioning Manager,
NHS Tower Hamlets

By streamlining management, focusing on outcomes rather than cost, improving procurement practices, encouraging cooperation and synergies across services, eliminating waiting times so that investment is not made in chairs the child will have

outgrown by the time he or she receives it, and ensuring wheelchairs are not over-specification, the efficiencies modelled by Whizz-Kidz are achievable in all areas, and equipment and services will be available to many more of the children who need them.

False economies

When children are not provided with the right equipment at the right time, there are financial costs down the road which eclipse the cost of the equipment, justifying purchasing it from the outset, even before considering the dramatic human costs of not doing so. An outcome-driven approach to cost analysis must take into account the longer-term costs of failing to meet these children's longer-term needs.

"We have provided a young lady with a wheelchair. That has taken £100k out of the education budget for classroom assistance.... By investing now, there is quality of life, but there are also savings across the board, things like putting a seat riser on a chair brings the seat high up and could prevent the need to modify kitchens, and to modify a kitchen will cost you £15-25k. We can put a riser on a chair for £800. If you start adding these numbers up, we see a lot of kids who are not getting through the eligibility criteria, although what they need is a very, very simple piece of equipment. By providing something which might cost about £800 or £1,000, the young person is getting what they need and there are savings to be accrued elsewhere."

Ian Legrand,
Strategic Service Advisor, Whizz-Kidz

The experts were in agreement on this point.

"Providing a riser on a chair for education means they can access all areas of the national curriculum without the need to buy special tables, and alterations within the school, and sometimes carers. So, by just investing, as Ian says, £800 for a riser, makes the life of a young person so much more accessible and fulfilled."

Judith Davis,
Head of Clinical and Regional Services,
Whizz-Kidz

In contrast to the £800 riser, providing desks of the right height costs approximately £3,000 per child in mainstream education. A full-time classroom assistant can cost over £12,000 per year (Connexions Direct, Careers Database – starting salary).

"I wasn't using my chair as much as I wanted to as I was scared of taking my powered chair out, but my confidence has risen, you've got to be confident, know what you want to do and how to achieve this. The chair from Whizz-Kidz has helped me so much as it has a riser on it and helps me be at the same height as my peers. I'm so grateful as I'm trying to enjoy life to the full."

Karl Woods,
Whizz-Kidz Ambassador and volunteer

Moreover, without the right equipment, children can face painful and expensive surgeries that otherwise might have been avoided.

"I think for me one case which sticks in my mind was a lad with Duchene's. It was quite a predictable prognosis, and a Duchene's spine curve can collapse very quickly. I know the delay meant this child then needed to have surgery. [With earlier provision] he wouldn't have needed to go through surgical procedures for a spinal operation which again has its own risks attached to it. If he could have been seen and given the right seating, his spine would have been protected and he wouldn't have gone that route."

Kate Hallet,
Senior Mobility Therapist, Whizz-Kidz

Small changes can make a big difference

Even something as simple as providing correct seating can prevent pressure sores. Pressure sores are very common among wheelchair users who have incorrect support. If not caught early, hospitalisation is needed. Many other complications from the sores can arise including, in extreme cases, septicaemia. On average, each pressure sore costs the NHS £4,000 (taken from the national tariff) in medical care. Regardless of any financial benefits, the human costs alone justify investing in the small changes that would prevent the sores. One particular girl had to wait 18 months for an appointment at her local NHS wheelchair service.

Small changes might cost nothing extra, and might be the result of a special attention to detail by the staff, like a minor adjustment or a piece of advice.

By being efficient, taking a longer-term perspective on cost, and focusing on small changes wherever possible, it is realistic for wheelchair services to make a very big difference without substantial additional investment.

“Greater knowledge among staff doesn’t require huge amounts of finance. If they are knowledgeable about wheelchairs for children it helps. It only takes one thing to make a wheelchair really difficult to use”

Jamie Green,

16 year-old Whizz-Kidz Ambassador
and sixth form student

“This girl was in severe pain, severe discomfort, and this was the only seating that she had and she was expected to sit in this all day, every day, yet this wasn’t regarded as an urgent referral for priority seating.”

Kate Hallet,

Senior Mobility Therapist, Whizz-Kidz

VIII. Conclusion and Recommendations

In conclusion, reform of wheelchair services throughout England is both desperately necessary and eminently achievable. For the chance to contribute equally in society, mobility-impaired children and young people need to experience independence and basic comfort as early in their lives as possible, and maintain it consistently throughout their development. Wheelchair services in every area must provide children and young people with the right equipment, based on the right assessment, at the right time. This standard of care has been proven achievable by Whizz-Kidz with specialised paediatric staff, dedication to children and families, holistic outcome-driven assessments, intelligent procurement strategies, and a sensible long-term approach to cost management.

What do we do next? The All Party Parliamentary Group for Paediatric Wheelchair Reform recommends:

Prioritisation: Ensure that paediatric wheelchair reform is spotlighted and placed very high on the political agenda. Apply political pressure to ensure that reformed paediatric wheelchair services are now a top priority within the wider NHS reform agenda.

Articulate minimum standards: Articulate uniform standards which prescribe nationally the level of care that paediatric wheelchair services provide and, very specifically, the outcomes that must be achieved. This specific guidance should be accompanied by follow-up performance monitoring and on-going dialogue with providers to ensure standards are maintained.

Initial investment: Although efficiency, procurement strategy and a sensible long-term approach to cost control are very effective in making wheelchair reform achievable, there are some areas that will need additional funds to institute these necessary changes. For all the reasons outlined in this report, initial investment in such improvements will prevent human and societal costs down the road and, ultimately, lead to wider savings in health and other public services.

Joint working across local and national government departments: Consideration of collective costs of inadequate provision – across government departments, the NHS and local authority budgets – highlights the need for effective leadership and coordinated action to reform wheelchair services and achieve wider benefits to society, the government as a whole and better outcomes for disabled children and young people.

Roll out of proven service models: The Department of Health must work closely with those organisations already leading the way in effective procurement, assessment and delivery of wheelchairs to develop an implementation plan that delivers improvements to services across the country and ensure that all disabled children and young people have access to the right equipment at the right time.

IX. Addendum:

Some personal experiences

As one of its many creative initiatives, Whizz-Kidz has recently launched an inspiring campaign called **Fast Forward**. The goal of the campaign is to assemble a petition urging the government to reform wheelchair services for disabled children. Whizz-Kidz has created a micro-site to host the campaign, allowing people to add their names and offering them the opportunity to describe their experiences. Below are some of the personal experiences that people have shared on the site. These comments offer insight into how individual families are personally impacted by the wheelchair services as they currently operate in the UK, and highlight the human argument for instituting reforms as soon as possible.

**Name: Anonymous Supporter
on Jan 22, 2011**

Comment: Our son had terrible delays regarding provision of his wheelchair in spite of him quickly losing the ability to walk. Coupled with a move of area (and told that we had to start again at the beginning of a waiting list in the new county) we waited... and waited... and waited and were still waiting nearly 2 years later at a point when my son couldn't even weight bear! If it wasn't for charitable funding stepping in quite quickly providing my son with a proper indoor/outdoor powered chair which suited his needs perfectly, he would quickly have lost complete independence, confidence and self-esteem – ironically when this is a time when he should be gaining independence from his parents.

Name: David, on Jan 20, 2011

Comment: Our local wheelchair centre gave our daughter a manual chair they admitted she was almost too big for, this after an 11 month wait to get it. It was also cobbled together from parts of three wheelchairs. It works and we use it, but the wheel and seat alignment means that it's hard work for her to push and doesn't encourage independence.

Name: Olwen, on Jan 20, 2011

Comment: I have worked with youngsters who need wheelchairs and have seen the benefits a good wheelchair can make to the person's mobility and sociability but also to their attention and communication skills enabling them to get the most out of their education.

“I always say that my wheelchair is my shoes. At the end of the day, it's a pair of shoes to me and it gives me the ability to lead an independent life. You wouldn't think of sending a child to school without any shoes...”

Ruth Owen,
Chief Executive of Whizz-Kidz

Name: Clare, on Jan 19, 2011

Comment: Children's wheelchair services are in a poor state and urgently need reform, so that each child can get the chair that suits them as soon as possible, without missing out on important years of their life!

Name: Louise, on Jan 20, 2011

Comment: The NHS are supposed to make people better – the wheelchair my friend's son was given by the NHS made him worse. One would expect them to be the experts. My scepticism towards the NHS increases daily.

Name: Rebecca, on Jan 17, 2011

Comment: We waited 2.5 years for a our daughter's wheelchair (she is 5 now) to then be given something to make do with – it shakes and rattles her till she screams, but according to wheelchair services it's all they can offer. Our children are not all the same! We don't all wear the same shoes; let our kids have what they need to live life!

Name: Rachel, on Jan 17, 2011

Comment: My 3 year-old son was given an unsuitable wheelchair, one not designed for a young, active user. It tipped forwards with him in it. He landed face first with his wheelchair on top of him. The chair was then replaced with one which was too heavy for him to self-propel. We complained to the Chief Executive of the PCT and received a letter saying "sometimes compromises have to be made". A choice between being safe but unable to move independently or being in danger but mobile is not an acceptable compromise.

Name: Lena on Jan 17, 2011

Comment: Having the correct wheelchair is so important, my daughter is a wheelchair user and one of my friend's little boys has recently had a nasty accident in an unsuitable wheelchair given by the NHS. Our kids need the proper equipment, it needs to be individually tailored to meet their needs and safe for them to use. Our kids deserve the access to live a full life, even though they have disabilities and providing the means for them to thrive is so important.

Name: Donna, on Jan 17, 2011

Comment: My son's NHS wheelchair weighs more than him. Yet he was meant to self propel it.

Name: Tina, on Jan 17, 2011

Comment: We have previously waited 5 years for a condemned chair to be replaced. Currently we are waiting 4 months for a chair to be reviewed that is having an impact on the breathing issues of our terminally ill child and still no appointment.

We live in Lincolnshire now, but have had problems in Lancashire, Wiltshire and the Isle of Wight in the past.

Many more personal testimonies can be read on the Whizz-Kidz website:
<http://www.whizz-kidz.org.uk/fastforward/fastforward-signatures>

