

The Future of Wheelchair Services – Any Qualified Provider?

*DOCUMENTS AND COMMENTS COLLATED BY
THE POSTURE AND MOBILITY GROUP*



POSTURE & MOBILITY GROUP



Foreword

This document has been compiled from letters and comments made in response to documents published by the All Party Parliamentary Group for Paediatric Wheelchair Reform (June 2011) and by Frontier Economics / Whizz-Kidz, and also to the Department of Health plans to extend patient choice by implementing a system of using Any Qualified Provider (AQP).

During the course of gathering these documents, we have been put in touch with the AQP Wheelchair Services Core Team and this foreword is added to summarize the current situation.

The timetable for this work is described on the Department of Health website:

- By 31 July: PCT clusters to be identified to develop an implementation pack. **For wheelchair services, the chosen clusters are the East of England and the Southwest.**
- By 30 September 2011: The clusters were to gather feedback from patients, patient representatives, healthcare professionals, and providers on **local** priorities.
- By 31 October: As a result of this feedback, clinical commissioning groups should have identified 3 or more community or mental health services for implementation. **This is the point at which we will find out which, if any, commissioning groups have chosen to implement AQP for wheelchair services.**
- By September 2012: Clusters should have implemented a system of Any Qualified Provider for the chosen services in their areas.

We* have had an initial teleconference (5 October 2011) with the AQP wheelchair services team, which is being led by Russell Foster, QIPP Procurement Programme Manager, East of England Strategic Health Authority, and consists of other individuals involved in the East of England and South West, many of whom were also involved in the original pilots run in those areas. Unfortunately, although the recommendations from those pilots were presented to the Department of Health last March, they have yet to be released into the public domain.

Some important points which were made clear during our discussion were:

- The team are strongly recommending that wheelchair services be considered as a whole, and **not** be divided on the basis of age. (Although the DH website relating to AQP still specifies **paediatric** wheelchair services, with **adult** wheelchair services to be considered in 2013/14).
- Provision of wheelchairs for **short-term use** is **not** included.
- Provision for those with **complex needs** is also **not** to be included.
- At this time, other assistive technology needs such as assistive communication technology, 24 hour posture management, and conjoined working with other budgets are not included.

The AQP team are working on 5 work streams:

- Specifications, for assessment as well as for equipment provision and ongoing support

- Pricing methodology and currencies
- Service standards and national, outcome based Key Performance Indicators
- Development of an Information Pack for users
- Development of templates to be used by local commissioners as part of their Community Service Contracts with providers

The team is producing draft specifications for initial consultation within only the 2 cluster areas. These specifications will be modified as a result of this consultation, and then they will be made available to a much wider group (geographically as well as by sector) for comment. We therefore expect the specifications to be available to us at the **end of October**, and we are planning to organise another conference with the team around that time. We strongly advised that this consultation should be as wide as possible, and should particularly include user groups.

Implementation packs are expected to be produced by the **end of November 2011**.

Areas identified in which we feel we can advise and contribute include:

- Establishing criteria for identifying clients with “complex needs”
- Clinical competencies – existing national standards (CQC, HPC, etc.) that are considered appropriate.
- Tariffs - specifying criteria for defining levels of service and provision
- User groups willing to be consulted

The team are maintaining a list of “stakeholders” from which they will choose appropriate people and groups to consult with, and they are happy for us to provide them with contact details of anyone interested in contributing to the process. A more complete write-up of our discussions to date will be published on the PMG website shortly, with updates provided as they happen.

Please read this publication, spread the word, feed back your comments via PMG, BHTA, NWMF, RESMaG, or to your local MP or NHS commissioning bodies. We would appreciate it if copies of written communication with MPs about this issue could be sent to olwen.ellis@pmguk.co.uk, who has been collecting all submissions to date.

We think you will find some interesting and enlightening information within!

Carolyn Nichols

MCSP, Editor of the Posture & Mobility Group journal, and co-editor of this document

Olwen Ellis

Administrator of PMG

*and on behalf of the rest of the PMG representation team of 5th October 2011:

Barend ter Haar, Krys Jarvis, Henry Lumley, Dr Linda Marks, Peter Rowell

PREFACE

Wheelchair Services: What is needed to make Government policy work?

The Government has recently published a document, 'Operational Guidance to the NHS: Extending Patient Choice of Provider' (July 2011), in which inter alia are the proposals that, in certain areas, patients should have a choice from 'any qualified provider' (AQP). One of the key services to be included initially within this initiative is the provision of wheelchair services for children. The reason for the inclusion of paediatric wheelchair services on their own in the initial phase would appear to have arisen from the All Party Parliamentary Group for Wheelchair Reform report 'My Wheelchair is My Shoes' sponsored by the charity Whizz-Kidz. (APPENDIX 3).

Whizz-Kidz' summary of the success of their proposed model in a limited geographical area has emphasised their areas of success, but has failed to include other areas which have not been covered by their model. Additionally, some feedback from the sources listed above relates to experiences of the Whizz-Kidz model that is not represented in their sponsored reports. (see Section C).

This letter brings together the input of over two dozen clinical and other specialists from around the UK, including contributions from members of the Rehabilitation Engineering Services Management Group (RESMaG), National Wheelchair Managers Forum (NWMF), Posture & Mobility Group (PMG), and British Healthcare Trades Association (BHTA). It hopefully paints a broader picture than the selective approach of the Whizz-Kidz sponsored reports.

The need for a holistic view and coordination of provision

Provision for people with disabilities has been heavily the responsibility of health budgets, and thus the 'medical' model has usually prevailed over the last few decades, if not longer. However, suitable provision has positive impacts in not only the medical area, but also social, education, and employment areas, amongst others. Indeed, as a second Whizz-Kidz sponsored report, Frontier Economics' 'Social Return on Investment for Whizz-Kidz' Services', points out, for every pound spent there were from £10 to £25 savings to be gained. The point made in this report is that at best only 1-5% of these savings were made on health costs, and the rest from social, educational, and employment costs/benefits. One example of a holistic, integrated service is seen in Norway, which has probably led the world in integrating service supply to those with disabilities; one centre in each region assesses and provides for all the needs of an individual.

There are individuals in the current Government who believe in the benefits to the individual and the State of combining budgets from different departments. The idea of placing control of health budgets for each individual with GPs was a first attempt to go along this route.

What seems in conflict with this view is the current proposal to introduce fragmentation of provision by separating off the provision for children and their wheelchair equipment from a) the rest of the population, b) from an holistic view of the individual's needs for their support beyond a limited range of wheelchairs, and c) what individuals need when they are not in a wheelchair.

Any Qualified Provider?

However broad or narrow the service, the bodies mentioned in our introduction are all adamant that there needs to be a level playing field for all entities tendering to provide the service. The following points, amongst others, have been specifically mentioned:

1. There must be well-defined benchmarks and criteria for the *Qualified* bit of the AQP. It needs to be clear what tenderers will be required to prove as to their abilities, and how this will be monitored.
2. Well-defined benchmarks are also needed for the *Provider* part of AQP. What will be provided, for which clients, in what timescales, to what quality level, and how will this all be monitored?
3. There should be a national contract of standards, thereby minimising the potential for a ‘post-code lottery’.
4. The discussions around cost savings are important, but need to be presented in terms of which models of service and provision provide the best long term cost benefits for both the individual and the State, rather than being limited to short term price savings where service is commoditised around the cheapest equipment at the cost of whole life benefits.
5. There needs to remain in place a broad range of available solutions and equipment to help ensure the best outcome for each client.
6. There are very competent services within the NHS which are client-focussed and run a tight ship, who must be allowed to compete on a level playing field with other potential AQPs. For example, they should not be disadvantaged by not being exempt from VAT on their purchases. They should also not be disadvantaged because they can’t fund advertising campaigns and produce glossy presentations. The criteria to be considered and the parameters for making choices must be carefully guided, with the focus on the patient at all times.

Broadening the picture

There needs to be a broadening of the total picture so that the AQP is able to, and required to, cover the whole spectrum of need, including social, educational, and employment, rather than just the medical need. Specific areas requiring consideration include:

1. *Continuity of provision, maintenance and review, and record keeping*

In the past, the term ‘paediatric’ has covered individuals up to 18 or 19 years of age. Even within the plans to extend this to 25, this still presents the challenges around one provider covering clients up to a certain age, and another thereafter. At any arbitrary age the individual’s needs do not change. Indeed, the sort of children who are considered ‘complex’ and who therefore require specialist clinical expertise, will continue to require specialist input as they become adults and as they age. Within the spirit of Human Rights across Europe, there should be joined up rather than fragmentary provision as one ages.

The proposals should incorporate the need for continuity of medical and client records.

Ongoing review, as well as repair and maintenance, contracts must be included.

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2. Specialist support – the need for liaison to cover the breadth of related needs

Feedback from the clinicians mentioned above has shown that the current model offered by Whizz-Kidz appears to be cheaper because it does not include the costs routinely incurred by current wheelchair services, e.g. provision for postural seating needs, special seating needs, qualified rehabilitation engineers, and home assessment. Thus the model is limited and incomplete, and does not reflect the whole picture of the service provision required just on the health front, let alone the broader picture beyond just 'health'.

At the higher levels of clinical need (i.e. more complex and severe disability) it is essential that there are open and efficient links between the AQP and relevant surgeons, physicians, and other clinicians (related, for example, to spine or hip surgery, provision of alternative and augmentative communication, management of spasticity, provision of orthotics and prosthetics).

In summary

The Government needs to broaden its consideration of the needs of people with disabilities beyond the health funds being linked to the 'patient', to *all* funds being with the individual. AQP tendering must be on a level playing field, needs to be prescribed precisely, and needs to cover the broader picture, as opposed to covering only limited aspects.

Current plans seem to provide for one group of people ('children'), at the simpler level of need, and just for wheelchair provision. For administrative and purchasing economies, and for patient benefits, it makes better sense that there is one service that covers cradle to grave, simple to complex needs, health through social through education through employment budgets, and thereby looks in toto at the individual, where payment by results benefits the individual, the State, and society as a whole. In view of these various concerns we would ask that paediatric wheelchair services are not put out to tender.

A separate report (attached) has been prepared which brings together the detail in the numerous contributions from which this letter has been produced. These individual contributions present a great depth of insight, knowledge, and constructive comment.

The different Associations who have contributed to this letter would welcome the opportunity of working with the Government, to help refine and shape the current proposals developing them into an holistic service reflecting the needs of wheelchair users of all ages.

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Member of PMG
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PMG member
National advisor to the Executive committee

with contributions from

**British Healthcare Trade Association
National Wheelchair Managers Forum
Posture & Mobility Group
Rehabilitation Engineering Services Management Group**

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SECTION A: MOVING FORWARD TOGETHER

1. Lisa Ledger, Occupational Therapist, South Staffordshire District Wheelchair Service

Just a quick note as I don't know where to start with the Government plans - incredulous!!! How do they explain/justify separating a service for children? We have always been equitable in wheelchair services and if they do this it will make the issues of transition more difficult than they already are. More concerning is the lack of understanding around wheelchair services as a clinical service and there are different parameters of needs that are likely to need a different response. Also, they have no parameters of benchmarking for who is a qualified provider - guess we have to do this then.

I have drafted a clinical guide for commissioners and providers of services around the clinical nature and levels of need. If possible I also will share it with wheelchair managers and then hopefully it can be produced as a document to inform, amongst others, the new commissioning board.

Please note: This draft clinical guide is included at the end of this document. APPENDIX 1

2. Thurrock Wheelchair Service Team

INTRODUCTION

Whilst we would welcome an independent national review of Children's Wheelchair Services (WCSs) to ensure equity in eligibility criteria, resources, and budgets, we are very concerned by the recent 'All Party Parliamentary document' and media coverage.

Our GENERAL CONCERNS are as follows

- The report cannot be seen as impartial as parties who may in future benefit from the recommendations have been involved in the presentation of the document.
- The 'Expert Witnesses' do not include any representatives from National Wheelchair Managers groups, senior wheelchair service clinicians, PMG (Posture and Mobility Group), BAOT (British Association of Occupational Therapists) or CSP (Chartered Society of Physiotherapy), for example.
- No statistical evidence/outcome measures are included for NHS services as a comparison for the 'new model' proposed by 3rd sector.
- No counter discussion had been invited by the group (we are pleased that you are taking up the matter).

Our SPECIFIC CONCERNS are as follows

REFERRALS AND RECORD KEEPING

- Mechanism for referral, screening and prioritising needs clarification
- Networking of Outside Contractor (OC) with NHS colleagues in paediatric services, transfer of confidential information, and record keeping would need to be addressed
- Exchange of information re home, school, and 24 hour postural provision is invaluable – this would be needed to continue to ensure appropriate provision

BUDGET

- Would the tendering process be local or national? It would be necessary to ensure equity per capita, otherwise we would still have a postcode lottery for provision.
- Who would hold the budget and monitor the spend?
- Is there a danger that, should the children's budget become overspent by the OC, that other areas of the NHS Wheelchair Service budget (eg for adults) would need to be redirected. How are the charity's own funds used in conjunction with NHS funding?

EMERGENCY RESPONSE

- At present the Wheelchair Service, with its Approved Repairer and Rehabilitation Engineer Contracts, ensure that there is the facility for responding to urgent changes in situation (eg surgery/injury) for a long term user, and also to failure or breakdown of equipment. There have been countless examples of the team needing to respond, for example to ensure a child can be transported home from school or be discharged from hospital. The success of this service depends on all these facilities being in place and responding quickly. Where Outside Contractors have

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- been involved in children's provision for WCSs, they have used the services of the local Approved Repairer and/or Rehabilitation Engineer. Should the Children's Services be outsourced, would they be able to offer this type of back up service?
- Currently, clients with powered wheelchairs, also have a manual back up chair – would this still be the case?

REVIEW

- Clients are welcome to re-refer at any point, following initial assessment. We ensure children's families are contacted or seen regularly for review of their clinical needs, and adjustments and changes to equipment provision made as necessary. It would be important to retain at least this level of monitoring, to ensure there is no avoidable deterioration in posture, function, comfort, and pressure relief.

TRANSITION

- At present the children in our service are seen by therapists who have experience of working with adults and children, liaising as necessary with the client's care and therapy teams as necessary. The same team at the Wheelchair Service are involved into adulthood, which makes the transition much easier for the young person, their history is well known, and the family know the staff.
- With an Outside Contractor involved in children's provision, there may be inequitable criteria, provision, and budgets. Once the young person transfers back to the NHS Wheelchair Service, this may be a potential problem, as high specification equipment may not be automatically funded, and therefore private input and a greater call upon the NHS Voucher Scheme budgets may be required.

PROCUREMENT

- There have been great improvements in the past few years in purchasing procedures and lead times from manufacturers.
- WCSs are able to order direct from manufacturers, thus preventing further delays on lead times/delivery. We understand that the Outside Contractor would order via a third party, which would add to further delays. Also WCSs hold stocks which they are often able to use as final provision very promptly, or as an interim measure.

3rd SECTOR ROLE

- We have, in the past, welcomed the 3rd Sector (eg Whizz-Kidz and Action for Kids), in working with us to provide or top up finance for equipment that lies outside the remit of the Wheelchair Service. However, with this proposed change, we would lose this additional facility.

SPECIAL SEATING and REHABILITATION ENGINEERING SERVICES

- How would the Outside Contractor access these services, and how would the host WCS monitor the referrals, and potential expenditure
- Would the Outside Contractors have access to their own Special Seating and RE services for bespoke equipment and modifications? Would there be a regular review procedure?

BASE and INFRASTRUCTURE

- Where would the Outside Contractor be based?
- Would the NHS buildings and resources be shared?

CONTRACT MONITORING

- Approved repairer and Special Seating contracts are continually monitored and feedback is exchanged to ensure standards are upheld. There needs to be a facility in place to continue to ensure this is the case.

CLINICAL SUPERVISION

- Opportunities for clinical forum, support, training, and supervision currently exists in the WCS. A clinical supervision structure is important to ensure sound clinical reasoning and accountability.

As we stated at the outset, we are happy for a national independent impartial review of children's wheelchair services, but feel that the above issues should be addressed.

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Comments made recently about past experiences, and the proposed 'new model' of the provider -

"One size (wheelchair) fits all"

"It would be a disaster to transfer services"

"A wheelchair was still too large for a child, 2 years after provision"

"Anybody could offer anything, with the right amount of funding"

3. Linda Marks, External Advisor to PMG; Consultant in Rehabilitation Medicine (Retired)

One aspect of supporting our colleagues in learning to become competitive is showing our positive outcomes, which is why I was keen for PMG to get GAS (Goal Attainment Scaling) scores adopted across our services. This measure seems very appropriate for our services as it can capture the straightforward and the complex end of our work - this is critical if we are to get away from the 'logistics' view of what we do.

The PMG response to Andrew Lansley is very important. One point is that 'competitive tendering' will actually disadvantage the NHS services. They neither have the personnel, the time, or the money to spend on preparing elegant presentations, statistics, and glossy brochures - so they will be immediately disadvantaged. I've been through such an exercise, and even with top level support from my Trust (EXEC Board members on the presentation team) we spent HOURS and HOURS of time, let alone meeting on Bank Holidays and working till the wee hours of the mornings. Most Trusts won't be in a position to support this kind of activity so NHS services will go under by default even if they are better than any of the others.

4. Henry Lumley, Group Manager - Rheumatology & Rehabilitation, Southmead Hospital, Bristol

If you want to offer choice then we'll have some of that but we play the game on a level playing field. The commissioners have to take responsibility for what they are introducing which means the cost as well. There needs to be a tariff set and that should apply to any provider. It should cover the full service, including assessment, delivery, re-assessment, fitting, tweaking, repairing, etc for the full episode. I would be happy to compete with any of them but it must be fair. If the equipment is wrong and has to be replaced, then you don't get another tariff. You carry that cost. Like the CQUIN targets on re-admissions within 30 days.

VAT is an issue. A charity may be able to provide the chair free of VAT. Certainly if an individual buys disabled equipment as a disabled person then it's zero rated. If the NHS buys and issues we can't recover the VAT. This needs resolving.

The DH guidance clearly states that AQP is about quality not price/cost. It only works if there is a common tariff that everyone gets paid. Lynne Turner-Stokes still heads a group looking at HRGs and tariffs for rehab and has just asked if I'd like to lead a project looking at tariffs for all our services. (I'm not sure I would but I suspect I should and probably will. I need to get some advice from my Trust first). This could help.

Locally, our SHA are saying they want to push all wheelchair services down this route (adult and paediatrics) but then talk about separating assessment from provision, suggesting the choice could be about who provides the equipment. I have said this would be madness. You cannot separate provision. It just wouldn't be possible to issue a prescription which would enable a dealer/manufacture to issue a wheelchair/seating without the benefit of the clinicians fitting at delivery. You just can't do it.

5. Lone Rose, Physiotherapist, National Spinal Injuries Centre, Stoke Mandeville Hospital; ex member of PMG Executive Committee

Have just read your circular regarding the plans for wheelchair services. Speaking on behalf of the SCI (spinal cord injuries) lobby - if you would like to use some positive evidence for how wheelchair services have improved in recent years feel free to use the data presented at PMG in 2009 from the national surveys. This showed a distinct improvement in types of wheelchairs provided which led to less abandonment of wheelchairs (= better use of resources) and great satisfaction scores amongst users. Also the most recent standards produced by the wheelchair managers' forum in collaboration with others show that they have taken on board emerging evidence - e.g. having as one of the standards that active users should be provided with high performance lightweight wheelchairs in accordance with the recommendation from the Consortium for Spinal Cord Medicine (2005). So even though funding has not been increased in real terms the services seem to be able to move forward in accordance with evidence (for SCI anyway). No small feat. All this helps to foster greater equality of provision across boundaries, reducing the 'postcode lottery'. Putting these services out to private tender will presumably blow this completely out of the water.

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Above evidence not yet published as article but should be available soon on the UCL website as part of my MPhil dissertation. And then published as articles, is the plan.

6. Olwen Ellis, PMG Administrator

I am in the same situation as the people who are making decisions on wheelchair services because, like most of them, I don't work in a wheelchair service, and have never used one. It's only because I work for PMG, and live with Pete (rehab engineer), that I have come to understand that it is a service which fits perfectly into the remit of the NHS, caring as it does for the health of our most physically compromised citizens.

Prescribing a wheelchair is more than providing a disabled person with the means to move around, but most people don't understand this. Perhaps it is the nomenclature itself that is to blame: "Wheelchair Service" sounds more like an equipment store than a highly sophisticated health department which requires a range of clinical expertise, where Consultants in Rehabilitation Medicine, physiotherapists, occupational therapists, rehabilitation engineers and clinical scientists all work together to provide complex seating solutions for their patients/clients.

The reality is that these clinicians need high levels of skills to prescribe for complex postural issues, and by getting the prescriptions right, will save the NHS huge amounts of money further down the line - by helping avoid hospitalisation for a range of complications that would otherwise ensue, from chronic pressure sores to respiratory issues. It is true at all ages, but in particular while children are growing and developing, where the correct postural management interventions can improve their prospects radically. Preventative medicine at its best.

Because the majority of clients/patients remain with a wheelchair service for most of their lives, their postural and mobility requirements will change continuously, so that repeat assessments and prescriptions cannot be avoided. It can never be like having a cataract removed, or taking a course of antibiotics, which fix a medical problem. All prescriptions are for the condition at that time, until things change. Disability is, for most, a life-long condition.

The need for national standards for these services is as great as for all other NHS services: the postcode lottery is particularly prevalent in wheelchair services. PMG was set up to help change this, and is best placed to advise government departments about training needs, best practice and competency requirements.

7. Margaret Hannan, Clinical Scientist, Kings College Hospital

What I believe our organisation must do is demand that there is clear accountability during and after the process of opening up to any qualified provider.

- i) Commissioners must publish the results of their initial engagement with patients, healthcare professionals and providers regarding local priorities for extending choice so that inaccurate information can be challenged
- ii) The evidence for dissatisfaction with the current providers must be made public so that the impact of any change of provider can be assessed in the future
- iii) The potential benefits of opening up to AQP should be identified (just because there is current dissatisfaction in certain areas there is no guarantee that simply opening up to AQP will improve matters, eg if the service commissioners wish to control eligibility criteria and these criteria are the source of the dissatisfaction)
- iv) Clear service delivery criteria must be published as soon as possible so that all qualified providers have the same opportunity to tender for the contract and so that contract monitoring can take place
- v) The 'qualified' in 'any qualified provider' needs to be defined
- vi) Criteria need to take account of the ongoing maintenance of equipment (This does not have to be included in the service contract. Responsibility for maintenance could be passed on to the service user via insurance schemes, for example, but this needs to be explicitly stated if there is to be a change from the current situation where maintenance costs are covered directly by the service)
- vii) Monitoring of the contract should include some longer term outcomes, for example the lifetime of each prescription, perhaps giving some measure of the average yearly cost of the provision. This might help with identifying services that were able to deliver good value (perhaps better at getting the initial prescription right or providing equipment that might be more expensive but which lasted longer because of the equipment's potential for adapting to growth or change)
- viii) The emphasis in the white paper is on choice. Will there actually be specific contracts for providers in specific geographical areas? Or will there simply be a tariff system with any qualified provider being able to **offer** a

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wheelchair prescription service to any wheelchair user and charging for this on an individual basis (but not necessarily getting any work)?

ix) While each provider must take responsibility for providing data to support monitoring of the service, there should be some objective means of assessing the effectiveness of the provision. I note that much of the information supporting the effectiveness of certain organisations has been provided by the organisations themselves.

8. David Porter, Clinical Application Specialist, Dynamic Europe Ltd; PMG Executive Committee Member; Chair of PMG Research sub-committee

My view is that the terms of reference for the PMG political action group should focus on engaging with and advising policy makers. It is important we are not seen as simply resisting the suggested changes. However, given our concerns about what we think is being proposed, this might be easier said than done. Obviously we have all invested a huge amount of time and emotion into the NHS wheelchair services and want to protect the good things. However there will always be things that can be improved. If the political group can engage in the process, maybe this will help to nudge things in a more appropriate direction. Unfortunately, change for the better usually needs significant investment of time and resources and, given the current financial climate, it is very unlikely this will be available. It is more likely that these changes are connected with the aim of saving money. As others have said, at the very least the political action group should be trying to ensure wheelchair services can compete on a level playing field if services do go out to tender. Also, if it is inevitable that the wheelchair services do go out to tender, it would be good to push for certain parts of the service (i.e. those requiring greater clinical expertise and coordination with other parts of the NHS) remain within the NHS, perhaps allowing other parts of the service to end up being carried out by a different provider.

9. Dr Imad Soryal, Dr Martina Walsh and Dr Sudha Balakrishnan; Consultants in Rehabilitation Medicine

Qualified providers of wheelchair / posture and mobility services to people with long term conditions need to ensure that patient pathways are maintained and further developed in line with other NHS / Social Care services professionals. Patients accessing Local Wheelchair Services benefit from timely intervention of many rehabilitation services, e.g. spasticity management, developing an integrated and holistic management plan. Further development should be extended to include specialist charities e.g. MS, MD, MND, Whizz-Kidz.. For this to happen services need to further develop the network of professional, charitable and industrial links.

Multi-disciplinary assessments for those with complex disabilities, e.g. the management of neurological and neuromuscular disabilities, need to be protected with career pathways for professionals leading from student practitioner level to specialist within the rehabilitation field becoming commonplace. This network will encourage continuity of care (no longer a given in service provision) for patients as retention of appropriately trained staff becomes less of an issue and staff have established contacts to interact with. Services working in isolation should be discouraged and all service provision should link to larger (regional) organisations whilst maintaining their local autonomy and ability to tailor services to the local requirements. This is facilitated by a hub and spoke model which also ensures that the peripheral service providers are trained to recognise when, how and where to refer their complex clients..

Education and training of professionals should include all members of the multi-disciplinary team (Consultants, Rehabilitation Engineers, Therapists) and are best delivered at regional level (involving appropriate Higher Education Institutions, such as Coventry and Birmingham Universities) supporting all Local Wheelchair Service practitioners and assistant practitioner support staff. All services need to commit to continuing professional development.

Agreed national / regional commissioner specifications, policies and procedures should be developed which can be used to advise commissioner tariffs in line with activities. This will reduce the “post code” lotteries that currently exist. Appropriate Care Quality Commission audits should be identified and introduced, led by either national or regional groups. Medical device standards already exist to protect the health and safety of patients’ equipment.

The West Midlands “hub and spoke” model and its potential for future development go a long way towards addressing the above service requirements. As an example Birmingham Wheelchair Service have developed, with their commissioners, specifications that incorporate relevant CQC specifications and the service reflects the DH model. We are currently (for the past year) running a “shadow” cost and volume contract to test a method of specifying defined levels of service and provision, and therefore tariffs. We have also defined quality measures and as a matter of course set individual patient goals, followed by a questionnaire to test outcomes.

10. Dave Harrison, Clinical Engineering Services Senior Manager, West Midlands

Local and regional provision was discussed by a representation of local and regional staff with Donna Carr during a visit dated 20th April 2010. As a result of the DH work and Donna's visit, the Local Wheelchair Service completed a service redesign project that has never been discussed outside of the West Midlands. It was our interpretation that the group would receive DH feedback and have further opportunities for inputting into the programme.

Our interest is to protect / improve the levels of provision all of our patients/ clients receive and thank PMG, RESMaG and West Midlands Wheelchair Managers Group for inviting us to add further comments.

Reference "Any **Qualified** provider":

We would like to understand the criteria that exists to enable an organisation to become "qualified" and more importantly that within the criteria assurances exist to protect patients' assessment, provision and safety. The current levels of provision, to include the points raised in this paper, should be considered as the base line standard.

SECTION B: GROUP RESPONSES

1. Krystyn Jarvis, Chair of National Wheelchair Managers Forum

The current NHS providers offer an equitable service across all age groups ensuring children coming into adulthood can anticipate the same level of service. These services with limited resources are tasked to provide an efficient, cost effective service to all wheelchair users, and specialised clinicians will prioritise all clients with the most urgent need, very often with children being given priority. The NHS services' budgets are mostly taken up with complex seating and bespoke wheelchairs and so the high volume, low cost items are largely not supplied, therefore where there have been budget pressures it is the elderly, social user who has been most affected.

It should be noted that the (*Whizz-Kidz sponsored*) reports are based solely on the experience in Tower Hamlets, which is by no means typical of the rest of the country. Many of the statements that are made in these reports are irrefutable and express many of the concerns that the current providers of these services in the NHS have been stating for a number of years, such as the impact of well assessed, well-engineered equipment and timely provision specific to each child's needs on maximising their development. Therefore the 'invest to save' principle has been a long standing argument put forward to commissioners over the years.

The variation of provision of services around the country resulted in National Healthcare Standards being set by members of the National Wheelchair Managers Forum in 2005, and reviewed in 2010, in collaboration with a number of other professional bodies e.g. Posture and Mobility Group, British Society of Rehabilitation Medicine, emPower and Whizz-Kidz. These were subsequently presented to the Department of Health to adopt, and although this was refused, many services and commissioners implemented the standards as best practice recommended by the NWMF et al.

There are undoubtedly conflicting interests, as all the specific age groups and diagnoses will lobby for their interests. The reports also raise grave concerns, particularly as they advocate a fragmenting of wheelchair provision across age groups. The reasoning put forward by these reports can also be applied to young adults, those with long-term neurological conditions, trauma, war veterans, the terminally ill and the elderly. All have their priorities in terms of quality of life, independence, social interaction, reduction and prevention of further medical complications such as tissue viability, postural management and comfort.

Currently the NHS provides wheelchair and postural seating services from 'cradle to grave', giving a seamless service to all. To fragment the children's services away from adult provision solicits the question as to what happens when the child reaches adulthood. Transition to adult services has been a long standing problem for parents and children. It is

with a sense of relief that parents enter the wheelchair service and are informed that they will continue to be assessed by the same team.

As experienced professionals in this field of work we are aware of the many omissions in the narrative of these reports: there is no mention of the range of diagnoses encountered, the provision of highly specialised, bespoke postural seating, ongoing maintenance and repairs and the handling of returned equipment/re-cycling. We are then led to assume that the 'child in a chair in a day' is only targeting the least complex of cases, as bespoke solutions for a

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child with complex postural deformities cannot be addressed in this way, entailing the manufacture of individual items which cannot be taken off the shelf. It is these complex cases which NHS services address consistently, changing the equipment with the development of the child. The availability of a repair service is not mentioned; however, a timely repair service is essential, therefore has the cost of ongoing repairs to keep these children mobile been accounted for?

The overall apprehension regarding these documents is the misrepresentation of all the services in the country, the ill-evidenced claims being made and the lack of real narrative to support the claims, which on face value will entice commissioners and service users to believe changing providers of children's services would be of advantage. Further consideration regarding all aspects of service provision needs to be examined and the overall effect on all service users and the subsequent issues of creating two services out of one. If this proposal is adopted, will this lead to further fragmentation of these already comprehensive services, which will result in more costly overall provision. It is advisable at this moment to further examine each service within its locality prior to including the provision of children's wheelchair services in the initial 'any qualified provider' arena (Extending Patient Choice of Provider).

2. Dr Chris Daniel, Chair of RESMaG

RESMaG (Rehabilitation Engineering Services Management Group) is an organisation that aims to promote the work of Rehabilitation Engineers. It feels that the assessment and provision of children's wheelchairs by non-NHS organisations could have a deleterious effect on the safety of wheelchair users. Rehabilitation Engineers in the NHS are largely responsible for the correct provision of wheelchairs as well as postural assessments and prescriptions. Rehabilitation Engineers design bespoke solutions and authorise modifications to mobility equipment, including special seating and associated accessories.

Gains have been made in recent years by the DoH funding of an MSc course in Rehabilitation Engineering at Coventry University and the promotion of professionalism and accountability through the Voluntary Register of Clinical Technologists (VRCT). Further enhancement is promised in the programme of Modernising Scientific Careers (MSC) when Rehabilitation Engineers will become Healthcare Scientist Practitioners and will be subject to statutory registration. Currently registration with the VRCT is little known in private industry and the charitable sector and the MSC programme is confined to the NHS.

We would ask the NHS to consider the risks to wheelchair users in cases where provision is being made by individuals who do not have the experience, training and accountability of Rehabilitation Engineers in the NHS.

3. Ray Hodgkinson, Director General, British Healthcare Trades Association (BHTA)

BHTA considers it illogical to treat paediatric wheelchair services separately when whole life costs of supporting an individual need to be considered and addressed if the state is truly to achieve savings across not just health, but also social care, education and work budgets. We welcome the concept of "any qualified provider", but a clear definition of service requirement and the tariff that applies to it needs to be developed in consultation with all interested parties – making clear the scope and responsibilities – and "qualified provider" must also be clearly defined in context.

Defining "qualified" when looking beyond the arena of professionals registered with the Health Professions Council will require identification of means other than "qualifications" to evidence appropriateness – examples might be that trading entities (charities, social enterprises, limited companies etc) should be signed up to an OFT-approved Code of Practice; and that individuals working in the service should be signed up to a relevant body which has an appropriate Code of Conduct, looks at competence of those it admits, and which requires Continuing Professional Development.

SECTION C: LESSONS TO LEARN FROM WHIZZ-KIDZ EXPERIENCES

1. Libby Bradshaw, ex-manager of Tower Hamlets wheelchair service, 1992-2011

Critique of the Frontier / Whizz-Kidz report (Impact of Whizz-Kidz support to Primary Care Trusts, October 2010) refer to ADDENDUM 2.

i) **Page 16** figures and **page 20** conclusions: Many of the conclusions of the report are based on the figures on page 16 which cannot be accurate. Despite raising this with my manager and with Whizz-Kidz, Whizz-Kidz has declined to provide an answer as to the source of these figures but claim they are in the public domain. They have been unable or unwilling to point me in the direction of the 'public domain'. The key one is the claim we had £108K for staffing –

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our 2005/6 budget for staffing, RE contract and maintenance contract was a total of £268,718 for ALL users, I haven't got 2006/7 to hand but it would probably only have gone up by inflation. (The 2010-11 budget was £320,111. However, this figure is slightly academic as we were not allowed to utilise all this funding.) How they reached a figure of £108K for less than 300 service users when we had a total of 4,500 users I don't know. Our records and calculations at that time show we had a budget of approx. £94 per user to cover all staff, equipment and maintenance costs. Obviously a lot of those users are only using the repair service but, if their figures are being reported as an overall average, their costs per user (quoted at £800) are more than 8 times higher than ours were. The report concludes Whizz-Kidz is 60% cheaper.

ii) Shorter waiting times were achieved in Tower Hamlets for both children and adults – this was due to the huge injection of money to Whizz-Kidz (£600K over 2 years) and the original budget remaining in the service for the adults (over 26 yrs old) thus increasing the amount per capita. Various places imply this was due to Whizz-Kidz rather than acknowledging it was the increase in resources all round.

iii) **Page 7** final paragraph more or less admits the information is not robust!

iv) **Page 9** onwards compares Whizz-Kidz with the 'Typical PCT'. It is not clear what is meant by the 'Typical' PCT and it seems more like the worst case scenario from the Barnados and Whizz-Kidz report – most of the things listed under Whizz-Kidz were in place in TH service and all our neighbouring wheelchair services. **Page 11** on stock – our information has always been very clear and I am surprised if other PCTs are not expected to keep robust records of their stock.

2. David Allen, Rehabilitation Engineer, Tower Hamlets Wheelchair Services

I make these comments from my position of an NHS rehabilitation engineer finding himself in a service with Whizz-Kidz (WK) as a partner looking after the paediatric and young users (up to age 26) initially, but from April 2011 as the sole provider of service. It will be easy for many to see which service that is of course.

I am aware of the contents of the existing "Frontier" report and "My Wheelchair is My Shoes" together with any comments I have read in the regular press etc. I am also aware of the BHTA's comments on the same topic. Essentially I find myself having much agreement with the latter despite currently being an NHS employee not from the private sector. I have tried not to simply repeat anything already included in it. Like many I was a private sector employee in my pre NHS career.

I do not have access to detailed data regarding finance and user numbers etc. and would not expect to have, being a sub contractor's representative myself anyway.

I do feel that this whole issue is driven by WK and simply presents things in the best light for them. It assumes that others have little to offer. We in the NHS would never realistically be in a position to commission any reports anyway.

I am all for improvement to any services offered by the NHS. I am close to retirement myself and expect to be a user of various NHS services over time. I also have family members now who depend upon NHS services. I am certainly not opposing any improvement, but let us get things clear and on the commonly quoted "level playing field".

When WK arrived as a partner they enjoyed the use of a new budget provided for those young users only. The existing budget was retained for the "adults" with provision continuing to be made by the original NHS Trust wheelchair service. Put another way, this clearly amounted to a significant budget increase all round. Any improvement was not simply the result of more efficient provision - there was more money available overall.

I do see improvements in provision here but not simply because of a supplier change. In fact I believe it is very largely due to a funding increase. I ask myself what the same funding increase would have provided if passed to the existing wheelchair service. To maximise this they would have needed some warning to enable staffing and systems to be adjusted accordingly but I believe that is all. My answer is that the original service could have achieved *at least* the same improvements given the same opportunity.

When WK took over they were able to move into good modern well equipped NHS premises. The basic facilities to underpin any service were already available and continued to be used. The same facilities could easily cope with increased activity. The "critical mass" point applies here.

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NHS wheelchair services are essentially required to supply against agreed criteria. It can be argued that this restricts provision of anything at all to some and choice to others. We all have our own personal views and opinions of course but are nevertheless required to adhere to these criteria. WK seem to me to take much less notice of any criteria and so claim that service is better, whereas the NHS service staff would be criticised to not supplying to agreed criteria. Not a level playing field.

I consider that WK sometimes issues equipment which is more expensive than it needs to be. There is cheaper equipment that meets the statement of needs. Some of this more expensive equipment is perceived as “better” as it may look more attractive to some and perhaps carries a “premier” product image. This is described by some as “over provision”. The result can easily be heavier, less convenient items. I myself have heard users making much this comment. This cannot be an increase in efficiency. Yes I do realise that an end user may well not know what is going to be good or bad until he has had time to learn from actual use. However the experienced supplier should be able to point out at least some of this in advance.

The use of a single supplier seems rather strange. This happened very quickly but I saw no real evidence of evaluation or competition. It seemed to be taken as fact that this simply must be “better”. There are national NHS agreements in place for the purchase of most of the equipment used by wheelchair services. These are not used by WK who make purchases through the one supplier. Almost everything is delivered initially to his base and he re-delivers to any other location required. I have not been offered any evidence of this being more efficient, cheaper or faster. I have not considered any environmental issues which may relate. My own experiences working in other NHS wheelchair services is that it is certainly not faster! It seems to me that this way additional people must be involved in the supply chain too.

The use of specialist representatives from other manufacturers or suppliers is discouraged even if not banned. The use of the sole supplier also seems to assume that he has full knowledge of everything. I do not believe that person to exist. If they do then I have certainly never met him or her, and I have been working in such services for many years.

One way that has been suggested of providing equipment much more quickly is to provide “direct delivery” of some items under some circumstances. In short this is where no face to face assessment is carried out. The situation is evaluated from, say, a paper referral and basic chair delivery to the user is arranged immediately. This will usually be from a restricted stocked range. However there is nothing new here. Every wheelchair service I have worked with does essentially the same. It may not be called “direct delivery” or any other actual name but it happens frequently. No improvement or greater efficiency is seen by me.

Once WK had taken over the service they decided to change the basic range of equipment used. I and others have no objection to that. In fact I believe such action should be considered regularly. However there was no consultation, despite much experience being available from existing staff etc. I was not even informed until after the fact. I continue to work regularly in other wheelchair services where actually I find communication and consideration processes more open than here. Essentially I find much out by accident rather than design since the service was taken over.

3. Martin Davy, Managing Director, Delichon Ltd.

In the past, I have been a keen supporter of Whizz-Kidz. In 2005, and again in 2006, my wife and I ran the London Marathon in support of them and for a number of years they were the major beneficiary of our corporate charitable donations. Times have changed though, and now it seems I am not alone in feeling sceptical about the move to 3rd party provision of wheelchair services and in particular the involvement of Whizz-Kidz and the unrelenting focus on children in all of this. I am so concerned about where all of this is headed that I am in the process of organising a visit by our MP so we can show him some actual examples of the effects of recent changes, not the rose-tinted PR spin that those driving this new agenda would have us believe.

Our experience at Tower Hamlets is a mile away from the glossy report that proposes it as a model solution for service provision. Our experience in other centres which have experimented with alternative models of service provision (including Plymouth) is just as worrying. We have been told recently by a therapist employed by Whizz-Kidz that they are in effect compensating for a drop in donations by using NHS funding to cover what would previously have been supplied through their charitable arm. The severely involved adults with complex needs just seem to be forgotten in all of this. On numerous occasions we have seen children taking precedence over adults in clinics, and

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last minute list changes because children have been given a higher priority. In one recent instance this led to the delay of a delivery appointment and an adult client had to wait another month before we could hand over a bespoke item we had already made for her. In another case we have had a delay of 5 months in the supply of a powered chair (nothing more exciting than a Spectra XTR) – hardly a “seat in a day”! Our standard turnaround time for a Foam-Karve seat from casting to delivery is 2 weeks. We are no longer achieving anything like that speed of supply in any of the affected services.

Just to make matters more interesting for us, we have now been told by Whizz-Kidz that we cannot proceed with the selection process they currently have underway to choose their “Approved Seating Contractors” because we only supply one sort of seating and are not trying to sell ourselves as a “Jack of all trades” like some of our competitors. We are a specialist supplier, delivering a product which was my own invention in a unique way and are still one of the very few companies that genuinely can make “a seat in a day” – and quite complicated seats at that. This is a very worrying trend, and is a real blow to those of us who believe that the UK was actually better off having a variety of highly skilled smaller providers rather than the model of standardisation that applies elsewhere. If this is actually allowed to happen, then patients will end up being offered a more limited choice of chairs and seating from one or two big suppliers, with decisions made on the basis of what is easiest to supply and not what is clinically correct.

I know that some of the Whizz-Kidz therapists are not happy with some aspects of this either, as it undermines their professional judgement, and restricts patient choice. We already have the feeling that there is a problem recruiting staff with suitable experience in these new services. Certainly in Plymouth, none of the existing therapy staff were willing to transfer to either Whizz-Kidz or Millbrook, so there is a skills gap and a lack of continuity for patients. The therapist we have mostly been working with at Tower Hamlets is leaving to take up a post at Rookwood. Some of the more recent recruits have little or no previous wheelchair experience. All anecdotal stuff I know, but add it all up and it paints a depressing picture of what may face our patients in the future.

It isn't all about one charity though. If those responsible for making commissioning decisions think that it is safe to make cost-savings by getting rid of high-cost professionals (consultants, physios, OTs, REs) then they are bound to feel that they can get better value that way. Many users of more basic equipment will be largely unaffected. The vociferous active users will probably stand a chance of getting a better service. Some of the kids will get sparkly new chairs (although not necessarily appropriate seating to go in them). Complex seating clients just won't be seen as often – but that's ok because they take up a lot of time and their equipment is expensive anyway...

I can't help but wonder that if a charity can sponsor a government report, use that report to persuade one London service to change the way it works, pay for a private economic report which paints the rosiest of pictures, and then use that same report to persuade others to follow suit, then how much more influence should the industry trade body backed by 3 major professional organisations be able to achieve?

Given that wheelchair services often control sizeable budgets, I do find it extraordinary that they can be moved into the control of private companies or 3rd parties without a formal tendering process, and with no mechanism to ensure that the quality of care is maintained.

Change doesn't have to be a bad thing, as long as things change for the better!

4. Anonymous Locum worker

I have been asked to contact you with some feedback on my recent contact with Whizz-Kidz (WK) services. I work as a locum Occupational Therapist within Wheelchair Services. Since I commenced my recent locum position we have seen 33 children that had been seen by WK but have been re-referred to the service. 3 had equipment for handover. The re-referrals came mainly from parents and school therapists. All were seen in clinic with RE and OT. Equipment that was ready for handover was often deemed inappropriate due to lack of postural support or the wrong size. Parents reported difficulties with pushing the chairs; children's ability to transfer out of the chair was compromised, and on one occasion the chair identified for issue was second hand and had none of the recommended written information for parents.

Whizz-Kidz used to provide excellent service to families for powered mobility. My recent experience suggests that they have lost sight of their original core skills and in attempting to provide 'a chair in a day' are compromising their

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service. It is my recent experience that a proportion of children neither received a 'chair in a day', nor an appropriate prescription. I saw a child in clinic this morning. They had waited 5 months for a chair and now the lack of postural support is beginning to have a significant effect.

Writer wishes to remain anonymous

5. Colin Plumb, Former Wheelchair & Special Seating Service Manager, Plymouth DSC, 2002-2011

The first thing that needs to be understood is that Millbrook hold the contract for providing a wheelchair, special seating and maintenance service to the residents of Plymouth and South Hams. Millbrook in turn have sub-contracted the paediatric (although I believe this is up to 25 years) service to Whizz-Kidz and also the clinical supervision of the adult service to Whizz-Kidz. Although the Plymouth children's commissioner had initially directly approached and negotiated with Whizz-Kidz separately, it is my understanding that (apparently due to their charitable status and being registered as a children's charity) they could not be seen to be taking on the running of adult and maintenance services, therefore Millbrook front the operation.

I have already raised my concerns through the PCT board, NHS counter fraud team and my MP so I have no problem whatsoever in sharing information with PMG. I will forward some emails I sent to my local MP for your info. The shameful thing about this whole mess is that despite the counter fraud team recommending an audit of the process and despite the PCT board knowing that the procurement process was not followed, nothing was done. Skilled staff have been lost and the "seating specialist" taken on by Millbrook had no postural assessment experience at all. How can this be in the best interests of the patients and represent best value for tax payers' money????? It's beyond me.

There was no tendering process undertaken. No OJEC advert, no supplies2health notice, no service specification to tender against and no formal, transparent evaluation process. The existing service only received verbal notice that the service was being decommissioned a few weeks before the termination date.

I should point out that the Plymouth commissioner is of the belief that the service was tendered because back in 2009 a tendering process was undertaken for Plymouth's community equipment service and written in the tender advert document was the following line "There may be an option to extend the scope of the services to include paediatric **equipment**, wheelchair approved repairer **equipment** and functions, **equipment** associated with DGF functions.....all subject to proven cost effectiveness". There was nothing in this tender document about providing a clinical assessment service for wheelchairs and special seating.

From my own involvement with formal tendering processes I am strongly of the opinion that there has been a massive breach in NHS procurement rules as the commissioners have been unable to demonstrate that a tendering process took place, have been unable to demonstrate that an impartial evaluation process took place to demonstrate value for the public purse, and have been unable to demonstrate transparency in their undertakings.

I feel it's very important to point out that the new providers do not appear to be required to work to the same standards and targets that we had in the NHS. We had to record and report to the commissioners on a weekly basis the number of referrals we were receiving, assessments completed within the 6 week target, deliveries completed within the 18 week referral to delivery target, cost of equipment etc. It would seem that although the commissioner stated that the new provider would be contract managed in exactly the same way, in reality the new providers don't do this. I've attached some interesting documents for you. The freedom of information document clearly shows that data was available when we were running the service but is not available now that Millbrook is running it. The other

document/s shows the workings of the Plymouth commissioner and puts in black and white that no tender process was undertaken for the outsourcing of the Plymouth Wheelchair and Special seating service. These documents are in the public domain (I downloaded them from a Google search) so they can be included as well if you wish. (*we will provide on request – PMG*)

One final point is that the quality assurance and safety checks that the rehab engineers had in place to monitor the maintenance contracts do not happen with the commercial contracts. This is a major concern as you've only got to ask any RE around the country if he/she would be happy to let the maintenance contractor issue equipment straight to a patient without an RE check and the answer would be very definitely no.

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6. Peter Lane, Senior Rehabilitation Engineer, Exeter Mobility Centre

Whizz-Kidz (WK) confuse NHS wheelchair provision with social services and educational provision (*My Wheelchair is My Shoes* (MWIMS) page 13). See APPENDIX 3.

The report makes claims that earlier provision of a tilting wheelchair would prevent surgery (MWIMS page 13), but there is no clinical evidence to support this. At the Exeter Mobility Centre (EMC), we have had clients as young as 9 months old in tilting bases with special supportive seating systems, but we cannot predict the outcome for these children, hence we regularly re-assess them for growth and postural changes. There is research to support the provision of 24-hour postural management to improve outcomes for clients, part of which is met by the wheelbase and seating system, but would not predict a zero intervention of corrective surgery if adhered to.

My colleagues and I have first-hand experience of WK and the inadequate postural support of seating systems they have supplied. Their rush to source locally and supply quickly has highlighted how little their therapists understand about Neuro-muscular development in children. I know also of a 10 year old WK client who was supplied a class 3 powered wheelchair which is illegal under the Highway Regulations 1988 Act. Fortunately the chair was banned from the Primary School on safety grounds. The carer was repeatedly ignored when they requested a re-assessment for growth. Fortunately, they had the NHS to fall back on!

WK's mantra "a child in a chair in a day" (MWIMS page 7) is at odds with their claim to be holistic. We (EMC) routinely provide information to parents/carers allowing them to make informed decisions and choices regarding

equipment and how it fits into their daily lives. Clinicians have left WK because of the impossible pressure to supply "a chair in a day", when they know the prescription is far more complex. Please note that WK are now actively advertising for therapists from the NHS.

WK's CEO, Ruth Owen, claims that WK can provide even complex seating in 3 days, which raises grave concerns about their ability to complete a full postural assessment, and what best meets a client's clinical needs. These are amongst the most vulnerable and complex NHS clients, who will need continual review in provision for growth and neuro developmental changes.

WK claim to commission resources, but their preferred business model is to use only 2 or 3 suppliers for everything. They mention lowest prices, but I have seen receipts for powered wheelchairs of £7K to £8K supplied with no maintenance or servicing agreement (which is free in the NHS). It is difficult to see how this "opens up the market" for improvement and innovation as claimed.

As therapists and REs we are regularly asked for input before products come to market, because we have vast experience. Access to greater choice allows for better outcomes, contrary to the WK claims (MWIMS page 8). WK prescribe mostly modular systems that allow growth but not best clinical outcomes. They are easy to supply and often used in clinics where company reps play a key role. In the report they (WK) do not tell us about types of, or who will supply, the bespoke equipment.

The NHS services would benefit from the sort of attention we assume MPs gave to this WK document. Our services have repeatedly requested government review and help to improve wheelchair provision, and provide standardised best practice, but we have been ignored for years. We cannot allow these insidious reports (including the Frontiers Economics report) to ring the death knell of Paediatric Wheelchair and Special Seating provision in the NHS.

Our politicians should be ashamed that they are abandoning the NHS's most vulnerable patients to a market philosophy.

SECTION D: LETTERS TO MPs

1.

Dear Sir/Madam

I am writing to you to express my serious concerns regarding the proposal to outsource to the private sector paediatric wheelchair provision, currently provided by the National Health Service (NHS).

At present the NHS holds the wheelchair and specialist seating provision for paediatrics in experienced hands. Paediatric clinicians involved in the provision of this equipment have amassed a great wealth of knowledge and experience over the years, which surmount any service that can be offered by outside providers. These NHS clinicians, who may be occupational therapists, physiotherapists or rehabilitation engineers, have often chosen to enter this service particularly to further their specialist interests in the fields of paediatrics, neurology, postural control and motor development, or assistive technology, special controls, and equipment modification.

The Whizz-Kidz commissioned Frontier report infers that a 'typical PCT wheelchair service' is 'unlikely' to have 'paediatric specialists' available for assessments (Frontier report page 10). I would suggest that this generalisation is completely inaccurate, as can be proven by identifying the personal employment of many of the members, researchers and conference presenters who attend conferences on the subject of wheelchair and seating provision e.g. The Posture and Mobility Group National Training Event.

My colleagues and I work for one of the largest wheelchair services in the country; we serve a client base of 12,000 plus active clients at any one time. A large proportion of these are our paediatric caseload. We cannot prioritise our paediatric service clients above our adult users as we do not have ring fenced budgets, and to do so would be unfair and ageist. However "children" are not "lumped in with adults" (My wheelchair is my shoes page 9). In fact I would propose that by serving both adults and children, wheelchair service clinicians do not compromise their clinical ability, but enhance it. We are able to see and monitor the long term effects of our interventions regarding seating and wheelchair provision. This allows us to build long term, positive, friendly relationships with our clients. In doing so we accept and embrace our ongoing responsibilities to the children we serve, knowing they will become our future adult service users.

Our centre provides regular wheelchair service clinics for paediatrics in special schools, learning disability units, locality hospitals, and NHS service centres; we also attend clients in their own homes. Our eligibility criteria are not used to "exclude users based on the category of specific disability" (My wheelchair is my shoes page 11) but to guide the clinician in prescription or protect the user or general public. The child's family and representatives are always invited to attend appointments, and the children are assessed by a seating team comprising of a rehabilitation engineer and a specialist seating therapist. Equipment provision is not confined to manual chairs as is suggested (Frontier report page 11) by Whizz-Kidz. In fact we provide equipment to meet clinical need, ranging from basic manual, through lightweight active users chairs and from indoor powered to indoor outdoor chairs with dual or special controls. We also offer vouchers to upgrade equipment or enhance client choice.

The Frontier report statistics identify Whizz-Kidz involvement from the period April 2008 to March 2010 (Frontier report page 13); this shows a maximum number of 21 assessments per month in Tower Hamlets with a maximum of 7 reviews per month. In our service it is not unusual for a specialist seating team to see 12-20 children in a single day's school clinic. From this comparison it can be easily established that paediatric demand on our service is considerably higher than Whizz-Kidz have previously experienced.

Posturally challenged or mobility compromised children in our area are seen by our specialist clinicians from the developmental age at which they would be expected to be able to sit independently (approx 8 months) and they may remain service users throughout their lifetime. We complete holistic assessments of all our clients, which encompass full physical assessments of neurological and developmental potential. We also collate and record relevant information from all parties involved with the child on psychological, environmental, and lifestyle influences which may influence our choice of clinical prescription. We then order and deliver that equipment as quickly as our suppliers can get it. Our current service target time set by our service commissioners is for 18 weeks from referral to equipment delivery. To my knowledge nobody referred to our service has had to wait for "12 to 13 months for initial assessment and roughly the same time again for equipment provision" (My wheelchair is my shoes page 6).

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Given that the above factors gathered at the initial assessment are all relevant to the clinical needs for provision, I would suggest that Whizz-Kidz “child in a chair in a day” programme (Frontier report page 11) is not only unrealistic for most children with complex needs, but is likely to result in incorrect or inappropriate prescription of equipment. We have recently had our attention drawn to a case in our area where Whizz-Kidz had issued equipment which was above the stated weight limit for a pavement vehicle to a child who was below the legal age to use it. On hearsay from parents this is not an isolated case.

The Frontier report suggests that by using three preferred suppliers and a dealer as a strategic partner a better value-for-money service can be achieved (Frontier report page 11). This must prejudice their clinical decisions and bias their prescription choice. By *not* limiting themselves to specific suppliers but by prescribing equipment based on the presenting clinical need, NHS clinicians are able to assess without manufacturer bias and prioritise the clinical needs of the child above the loyalty to a manufacturer to use only their product.

Once referred into our service we operate an open referral system for our clients: should any problems be identified with postural control or equipment a review can be requested by either parents or GPs. We also offer planned maintenance service and have contracted approved repairers on call should our service users need them. This is in contrast to the scenario of a ‘typical wheelchair service’ depicted by the Whizz-Kidz document (Frontier report page 12).

Whilst all those involved in the current system of wheelchair service provision would acknowledge that there are areas of weakness in the service as it stands, these can be primarily attributed to lack of funding and resources. There is a very real danger here that by allowing privatisation and losing the specialist services of NHS provision of paediatric wheelchair services, we are going to throw our baby out with the bathwater.

In conclusion, I consider, given due analysis and consideration, that both the Frontier report (2010) and My Wheelchair is my Shoes (2011) (the two documents on which the future of wheelchair services for paediatrics depend upon) are heavily biased and littered with factual inaccuracies and unfounded subjective comments, which have little or no basis in the truth.

The NHS wheelchair services have historically provided a clinician led service which strives to provide best practice for our users, giving a client centred assessment and providing equipment prescription based on clinical knowledge and evidence led research within a limited budget. The Whizz-Kidz model cannot and will not provide a better service to our paediatric client group and I would suggest that we make a very strong stand to defend against this motion.

Yours sincerely

Mrs Marion May Msc Bsc (Hons)
Senior Centre Therapist
Exeter Mobility Centre

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2.

**Mr Peter Luff MP
House of Commons,
London SW1A 0AA
18 August 2011**

Dear Mr Luff,

I am a Rehabilitation Engineer (RE) employed by Birmingham Community Healthcare NHS Trust at the West Midlands Rehabilitation Centre (WMRC), Selly Oak, Birmingham. WMRC contracts RE services to all Wheelchair & Seating services within the West Midlands. I have been employed in my current role since August 1988. I work primarily in the Worcestershire Wheelchair & Seating service within the Worcestershire Health and Care NHS Trust (WHACT)

I last wrote to you in February 2010 regarding proposals to radically change the provision/structure of wheelchair and seating services in England and the National Wheelchair Service Advisory Group (NWSAG). Within the West Midlands we were able to meet with Donna Carr (part of the NWSAG) on 20 April 2011 and present our constantly developing and collaborative work.

The purpose of this letter is to highlight some of my concerns regarding the implications of recently issued NHS document (Gateway reference 16242) dated 19 July 2011, Operational Guidance to the NHS, Extending Patient Choice of Provider, in particular some of the reference material which may have had some influence on its formulation.

The recently published All Party Parliamentary Group for Paediatric Wheelchair Reform report "My wheelchair is my shoes", making the case for wheelchair reform June 2011 makes some inaccurate assumptions. It is unfortunate that a representative from a Wheelchair & Seating service was not in the group of Expert Witnesses. I have highlighted a few issues raised in the aforementioned report which are of concern:

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"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:

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

It is vital to understand that a wheelchair with supportive seating is only part of the issue. Children and adults with the need for postural support should be supported appropriately at all times during their daily routine. 24 hour postural care is an area sadly neglected. I have often seen children and adults who are understandably uncomfortable and poorly supported after spending extended periods in their wheelchair due to unavailability of other forms of supportive sitting/lying equipment. I would not expect anyone to be comfortable if spending 4 hours or so seated in one position. Often the wheelchair and supportive seat is the only option available and therefore is "over used" and feels uncomfortable due to inappropriate use.

Page 7

"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"

Within the Worcestershire and some of the other West Midlands services, we have negotiated preferential terms of provision better than the framework agreement. Contract prices are constantly monitored to ensure best value.

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"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 ever has been....."

Consumer led provision is great for the customer but one needs to take a view of the bigger picture to ensure that costs of maintenance and repair do not escalate. Economies of scale result in better costs of parts for repair agents and familiarity with equipment results in a more timely response when repairs and maintenance are required. The service has to be aware of the needs of **all** the customers we serve.

I would not disagree that reform is needed. Certainly within the West Midlands and particularly in Worcestershire we have worked tirelessly to advance and improve the service for many years, our main driver being the NHS Modernisation Agency Wheelchair Services Collaborative announced in November 2002. We have also been drivers of innovation working collaboratively with equipment manufacturers to improve equipment design and function and liaise regularly with them for this purpose.

It should be noted that the Wheelchair & Seating service is one of the few community services which is seamless in service provision. We assess and provide from "cradle to grave". Parents see this as a tremendous benefit as they expend great efforts with other agencies during the transition from child services to adult services. I agree that paediatric provision is extremely important but so are other groups of our customers such as those with deteriorating medical conditions such as Multiple Sclerosis and Motor Neurone disease, not to mention those who have suffered strokes and are in need of mobility and seating support assessment to improve quality of life and mobility, independent or otherwise.

There are a number of other questions to raise:

With customer choice, how does the money "follow" the service user"?

Will the funds come out of existing wheelchair & seating service budgets?

Will customer choice also be available to those who have very complex seating and mobility needs?

How will ongoing assessments be funded, particularly if a customer has provision and then needs/wants change after a relatively short period?

When does a child transfer from children's to adult services?

Will there still be an accessible repair and maintenance service free to customers?

It may be fact that non-NHS service providers have improved services in some areas of England but there must not be an assumption that all services are poor, so let us not "throw the baby out with the bath water". One relatively simple change would be to introduce National Criteria of provision. This would assist greatly by removing the "postcode lottery" effect which is evident throughout the Wheelchair & Seating services in England.

During my 24 years or so service within the NHS I have experienced many changes and developments, many good, some poor. It often seems that there is change for change sake. I, together with many of my colleagues, am not against change as long as there are benefits for our customers.

I would finally like to raise one other issue. I have recently been given a copy of the "Frontier economics" report: Impact of Whizz-Kidz support to Primary Care Trusts. There are some blatant untruths in some of the general statements made in the report and I feel that these need to be challenged. I will be taking this forward via the National Posture & Mobility Group and will request that the matter is raised at the National Wheelchair Service Manager's Forum. These reports surely must be verified before being used as reference material although it is unclear if this was used as a reference for any policy formulation.

I would appreciate this being passed on to the relevant parties within government and any comments you may have.

Peter Rowell I.Eng. IPEM. Rehabilitation Engineer
Birmingham Community Healthcare NHS Trust, West Midlands Rehabilitation Centre (WMRC), Selly Oak, Birmingham

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3.

29/08/2011

Rt Hon Alistair Darling
22A Rutland Square
Edinburgh
EH1 2BB

Dear Mr Darling,

Re: Andrew Lansley's announcement - NHS services being opened up to competitive bids from the private sector.

I am a Bioengineer working at the Southeast Mobility and Rehabilitation Technology (SMART) Centre base at the Astley Ainslie hospital which provides wheelchairs and customised seating for wheelchair users throughout Lothian, Fife and the Borders.

I am writing to you as my local MP whose party I have supported for a number of years.

I have been following current developments in England regarding Andrew Lansley's, Secretary of State for Health, announcement that several NHS services are being opened up to competitive bids from the private sector – this includes some areas of wheelchair services in England. I have read that the Bill enters the report stage and third reading on September 6 and 7.

Reform of wheelchair services has been on the political agenda for some time, even prior to the current government.

Although this does not affect my current position working in the NHS in Scotland, I have considerable experience of working in England within wheelchair services.

My fear is that decisions on transforming wheelchair services will be based on recent adverse press for NHS paediatric wheelchair services, such as the Whizz-Kidz commissioned Frontier report (<http://www.whizz-kidz.org.uk/wp-content/uploads/2010/02/Frontier-Economics.-Impact-of-Whizz-Kidz-PCT-Support.-2010.pdf>) and the All Party Parliamentary Group for Paediatric Wheelchair Reform recent publication (also heavily influenced by Whizz-Kidz), My Wheelchair is My Shoes (<http://www.whizz-kidz.org.uk/wp-content/uploads/2011/06/APPG-Report-My-Wheelchair-is-My-Shoes-Final2.pdf>). Both these reports make the case for wheelchair service reform. However, these reports do not give a balanced view of provision in England but focus on a single experience Whizz-Kidz have had on taking over a single service in trouble, based in Tower Hamlets.

There is no doubt that there will be some wheelchair services that are in a poor state, providing a quality of service that is not acceptable. The number of these services is not known. Equally there are many centres providing an excellent service. I personally know of many.

The most important thing is that the excellent services should not be judged by a single example of a failed service.

I am not against privatisation if it results in a higher quality service. I also believe that reform is no doubt required in some services.

However, if reform is required, all parties should have an equal opportunity to tender for running a service; this includes the current NHS service provider. All parties should have to demonstrate their capabilities for running a good service and should demonstrate evidence for any claims made. The current NHS service should be given the opportunity to tender under the same criteria set out for the private or charitable sector. They should also be given support to do so. This will prevent good NHS run services being dismantled on the basis of unrelated service failures.

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Additionally, if private or charitable sectors do bid for wheelchair services it is important that a national contract of standards is produced that all services should adhere to. There is already a post code lottery within the NHS, bringing in the private and charitable sectors may only increase the post code lottery.

Please could you do everything in your power to ensure good services are given the opportunity to protect their service users by being able to compete if they come under threat of take over from the private or charitable sector.

Yours sincerely

James

James Hollington
Bioengineering
SMART Centre
Astley Ainslie Hospital
Edinburgh

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4.
improving lives



**Greenwich Wheelchair Users Service
Greenwich Community Health Services**
Memorial Hospital
Shooters Hill
Woolwich
London
SE18 3RZ

Tel: 020 8836 8536
Fax: 020 8856 5473
Website: www.oxleas.nhs.uk

19th August 2011

Dear Nick,

I am writing to you as the Manager and Clinical Lead for Greenwich Wheelchair Service to voice my concerns regarding the announcement by Andrew Lansley in July that, from April 2012, wheelchair services for children will be one of eight services to be opened up to competitive bids from the private sector.

I fear that this decision has been influenced by unfair, negative press and sweeping statements made by influential organizations without allowing the situation in both Paediatric and Adult wheelchair services in England to be properly assessed and to have the voices of those who work directly in this field heard. If these negative statements are to be believed it would suggest that a third of the 320 children in Greenwich who need buggies, manual or powered wheelchairs have their needs unmet. It is suggested that children are provided with adult type equipment instead of specific paediatric equipment, that young children who could be active wheelchair users are denied equipment, that children are often refused power chairs until they are 10 years old and that in a typical PCT wheelchair service there is no paediatric expertise. It also suggests that services waste money through inappropriate procurement processes and high management costs. I can assure you that this is not the case in Greenwich nor in the neighbouring wheelchair services of Bromley, Croydon, Lambeth, Southwark, Lewisham and services in Kent. Our services work closely to secure the best prices with manufacturers through consortium agreements and support each other with service improvements through the South East Thames Wheelchair Managers Forum.

Though the clinical team in Greenwich is small, we are supported by, and work closely with, a large, experienced Community Paediatric Therapy team who assess and treat children in the mainstream and special schools and we work closely to achieve maximum functional independence through the provision of lightweight manual wheelchairs or powered wheelchairs and provide appropriate special seating for those children with complex physical disabilities. There are naturally some financial constraints to equipment provision and access criteria are necessary to ensure fair access to the service. But we use these criteria to guide our decisions rather than to restrict provision and work with the child and family to achieve the agreed outcomes.

Children with long-term mobility needs are able to progress through the service, supported through their childhood and teenage years with a transition into adult hood that enables them to feel confident that the service is aware of their previous medical and social needs without having to start again in an adult service that knows nothing about them as happens in most other areas of health and social care.

In 2007, considerable time and effort was invested by the Department of Health and the wheelchair services in England to review the wheelchair services. Unfortunately the opportunity to compare services and achieve fair and appropriate investment to improve and reform these services was lost due to a lack of clear guidance or recommendation at the end of the review.

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No-one would deny that children throughout the country should have the same opportunities across all wheelchair services with appropriate clinical and financial investment and that at the moment there are inequalities of service throughout the country. I am very worried, however, that reports such as “My wheelchair is my shoes” all too often seem to rubbish the current wheelchair services and do not allow any good practice from other services to be considered and would suggest that the “Whizz-Kidz way” is the only way to go. Separating children and adult wheelchair services is not the way and offering this very specialist area out to tender is in my mind a dangerous thing to do.

There are many highly experienced Physiotherapists, Occupational Therapists and Rehabilitation Engineers in the specialist field of posture and mobility who should be allowed to influence both paediatric and adult wheelchair services nationally and the government should not be making national decisions based on a report concerning one or two services in London. By offering the paediatric service out to tender it will fragment the services and the opportunity to truly reform wheelchair services across the population of England will be lost. The government should consult clinicians and managers in this specialist field before it is too late.

Yours sincerely,

Maggy Hevicon
Physiotherapist/Greenwich Wheelchair Service Manager

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5.

Mr Greg Mulholland
Wainwright House
12 Holt Park Centre
Holt Road
Leeds
LS16 7SR

25th August 2011

Dear Mr Mulholland

I am writing to you, as my local MP who I have supported for a number of years, and as the chair of the All Party Parliamentary Group for Paediatric Wheelchair Reform.

I am a Rehabilitation Engineer working at Leeds Wheelchair Centre at Seacroft Hospital and at Wakefield and District Wheelchair Services on Trinity Business Park, Wakefield. I am also a member of Posture and Mobility Group whose aims are to advance and disseminate knowledge about the posture and mobility needs of people with disabilities.

Whilst I work in these centres, I am expressing my personal views and, I believe, the views of many of my colleagues. You recently published a report "My wheelchair is my shoes". This report was written by Sally Waters, the Public Affairs Officer for Whizz-Kidz, and highlights the improvements that were achieved at Tower Hamlets, an area which appeared to have a lot of problems with wheelchair provision, especially for children. The report includes statements from a number of prominent people involved with Whizz-Kidz and the Tower Hamlets area. What the report does not do is look at existing provision at other NHS centres and seek the opinions of recognised experts and organisations involved with the provision of wheelchairs and specialist seating.

If you had visited Leeds or Wakefield Wheelchair Services I know you would have seen a similar situation to the one your members found at Tower Hamlets. We have minimal waiting lists, we provide wheelchairs and special seating that are clinically appropriate, our Paediatric Therapists work alongside school therapists to provide appropriate equipment and overcome environmental issues, we work within the budgets available to us and we maintain all the chairs we have on issue.

Looking at a couple of the points you raise in your introduction, you state that 'there are still 70,000 children who have their mobility needs unmet. That is 108 children in each MP's constituency'. This is a very large number. Based on the Leeds and Wakefield client numbers I would expect the total number of paediatric wheelchair users in the UK to be around 90,000. It is difficult to find published data which relates to children only, but if this is the case, you are saying that very few of the children in the UK have their mobility needs met. I would be interested to know where your number comes from and whether you can identify some or all of the 108 children in your Leeds Northwest constituency who are without appropriate mobility.

You say that 'In Tower Hamlets there is no waiting list and the equipment provided is appropriate'. In Leeds and Wakefield District there are minimal waiting lists and the equipment provided meets clinical need. While the equipment is always suitable, it does not mean that it always meets expectations. We could provide 'more sophisticated' equipment, as Whizz-Kidz are able to do, but the funding is not available.

I imagine, in this current climate, you will focus on the fact that the 'model also offers a saving of 60% for each wheelchair issued'. Without the breakdown of the £1,100 average cost per wheelchair supplied by Whizz-Kidz it is difficult to know what this statement means. I understand that when they took over at Tower Hamlets there were significant start-up costs incurred - who funded this and are they included? Do the costs include the supply of special seating? A high proportion of the total Leeds special seating budget goes on the provision to children. Do the costs include the ongoing maintenance and management of the chairs on issue?

Within the NATIONAL Health Service why do different wheelchair services have to buy wheelchairs at different prices when there is one NATIONAL Health Service Supply Chain fixing the contracts? We could save a lot of money if the NHS purchased and supplied goods to the Wheelchair Services on a similar basis as any commercial organisation would do, at the lowest possible price, to all their sites nationally.

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While I am arguing for more NATIONAL arrangements we have seen successive governments push for competition and localised decision making, to the point where Wheelchair Services all have different eligibility criteria and prescribe a vast array of equipment. Now there is a Post Code Lottery nobody seems to want it. The only solution appears to be to open parts of the NHS to private or charitable organisations as they will be able to “fix it”. Why can’t these changes take place within the NHS?

In my limited experience the NHS is made up of some very hard working, conscientious and caring people who find this report and others like it unrepresentative and very demoralising.

I would like to see reports and subsequent decisions being made about the NHS based on facts and transparency; these are sadly lacking in this report.

I would urge you and your colleagues to come and see what is actually happening on the ground in the National Health Service.

Yours sincerely,

Chris Bayford,

Rehabilitation Engineer,

Leeds Wheelchair Centre and Wakefield and District Wheelchair Services

SECTION E: ADDITIONAL COMMENTS

1. Craig Egglestone, Clinical Technologist in Rehabilitation Engineering, James Cook University Hospital, Middlesbrough; member of PMG Executive Committee

Having now read the APPG report I feel it does not compare like for like provision within the NHS and refers to provision of powered chairs with riser and standing facilities. These are not available from wheelchair services ordinarily. It also mentions savings incurred when providing these types of chairs as opposed to providing a one to one carer or height adjustable desks in school, what it fails to realise is that funding for this is via the Local Education Authority and not from a wheelchair service mobility budget!!!!. We in the Northern Region have tried in the past for joint funding of riser function for a child in a school situation and although funding was agreed it never materialised. How they work out their average cost per unit to be approx £1100 is beyond me, as the powered chairs they have issued to children in our Area have been the likes of high end Permobil ones. Also I echo the comments of others the service around the country is so varied since services devolved into NHS in 1991.

I also intend to send an e-mail to my local Labour MP Jenny Chapman.

2. David Long, Clinical Scientist MSc CEng MIPEM, Nuffield Orthopaedic Centre, Oxford, OX3 7LD; former chair of PMG

It is vitally important that areas where NHS provision is healthy are not ignored. It is entirely feasible for the NHS to deliver these services. The transition of the child into an adult should not be forgotten. Personally, I think many adults suffer very poor services as the focus is so often on children. There are many, many vulnerable adults who are not articulate and are unable to advocate for themselves. Please can we ensure that this proposal does not increase the gulf between paed and adult services any further?

3. Jo Purvis, Occupational Therapist, Surrey Community Health Services

I work for a wheelchair service that has been going through a process of continual change since 2007 and is currently in the midst of procurement change, the outcome of which is likely to be that our current community health body will be run by a private company in the very near future. The rationale for this, we have been told by our Chief Executive, is because 'Change must happen'.

In relation to the evaluation produced for Whizz-Kidz. We read the 'evaluation' by Frontier Economics on the 'Impact of Whizz-Kidz support to Primary Care Trusts' some months ago with dismay, some anger, and disbelief that such a document would be taken seriously by a government department.

I have just learned today that Frontier Economics is a high profile company giving advice on the economics of change on a very wide range of issues, often to top levels of government departments, whose chairman is Conservative peer Baroness Hogg, wife of former MP Douglas Hogg.

The points we most immediately took issue with were these:

- a) The evaluation was done 'pro bono' - who requested it?
- b) The evaluation is not based on any properly collected data, being merely the reporting of 'detailed conversations with Whizz-Kidz staff', as the evaluation itself clearly admits on page 7. Why was there no scope to conduct a bespoke data collection exercise, we in public sector employment are frequently required to audit aspects of our service, I would have thought objective data collection and analysis was the least requirement of an evaluation like this.
- c) With a sweeping generalisation the evaluation also suggests on page 7 that 'the specific experience from which this analysis is drawn is representative of wheelchair services more widely'.
- d) The comments on page 9 and 10 about the comparison between a Whizz-Kidz and a typical PCT assessment are ridiculous. Contact and data collection prior to meeting a client/patient and holistic assessment is routine to occupational therapists in whatever field they may work, the suggestion that this is 'innovative' is laughable.
- e) In any case, the suggestion of a one off 'chair in a day' appointment does not tally with the preparation time that is

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actually required, even by Whizz-Kidz, to have correct data and equipment ready to allow a child to go home with a chair following a 'first appointment'. At a minimal level, is there an appropriate vehicle if required and ramp at home to allow the child to get home, do Whizz-Kidz care, or do they only see children for whom all the groundwork has already been done by wheelchair therapists doing the nitty gritty liaison work with other professionals?

f) In the case of our wheelchair service, I would say that we work entirely in the way Whizz-Kidz describe as their own way in terms of supply chain, on page 11, and we do operate with NHS bulk pricing and from a useful range of modifiable wheelchairs. Surely it is Whizz-Kidz who have learned this approach from NHS services; the opinion of them amongst NHS professionals is that they supply one off chairs that couldn't be economically maintained by a public service.

We hold stock assessment wheelchairs, and often use more specialised, loaned consignment chairs on planned days, and are able to take them out to clients' own environments by van if trial is needed. We also have a large stock of consignment cushions available for trial.

g) I would disagree with comments on page 12; we review clients on request, never mind the wheelchair, they may be deteriorating themselves or suffer some other problems requiring review or modification, such as a broken limb to be managed. In this team, any work for children is allocated without a wait unless it is something that really can wait a little while, like a physio referral for a mildly disabled child who is just beginning to outgrow a standard buggy. Any repairs that can't be dealt with by our approved repairer are seen by a rehabilitation engineer often the same day or certainly within a very short time.

h) What about children in need of highly specialised seating and/or specialised equipment carriage, whose referrals would undoubtedly slow the rate of provision made? How many staff were Tower Hamlets employing when Whizz-Kidz came in?

i) The tone of the evaluation seems to be that the 'right' wheelchair for every child is a powered one. This may be true for the majority of people who typically apply for Whizz-Kidz funding but is not the case for every young wheelchair service client.

In relation to the private bidding for provision of public services:

I would also say that changes made, and still in process, to this team since 2007 take us further and further away from working in a way that allows us ease of access to appropriate equipment and to making our own plans as a professional and informed team. We used to have a base where we held our own stock, running clinics from which people often went home with a chair in a day. We understand that coming changes planned by our Chief Executive will aim to have us working from home (with what equipment!!?) along with other community health staff.

Our experience of working with private companies for equipment provision/maintenance using public sector funding has been that they cause increase in spending levels, using only brand new stock, sometimes for limited use, with poor stock control and very slow service. The only exceptions to this have been Medequip and T Brown in the Kingston area, in my experience. Control of such private companies should remain with suitably informed and qualified staff who understand all the processes and potentials for system abuse, not managed by finance departments from ivory and disinterested towers. I worry about the handing of public services over to those whose motivation is profit. See what happened to the handing over of hospital domestic services to private companies away from nurses, in terms of nutrition management and hygiene control.

Thanks for the opportunity to spur the recording of some of our thoughts. It's a shame a national response has been left so late, and although I now have the Whizz-Kidz document 'My wheelchair is my shoes' I haven't been able to read it properly yet, except to say from flicking through it that the comments in it are mainly from Whizz-Kidz staff or ambassadors and are therefore bound to be biased in favour of their view. No one has asked us what would work best. Nor for our direct opinion of what would work best.

4. Alison Johnston, Physiotherapist, Bromley Wheelchair Service; member of PMG Executive Committee

In Bromley we run a very good paediatric wheelchair service with timely assessments and provision of equipment. I know this is also the case of many services around the country. We were visited by Whizz-Kidz to discuss the service

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they offer (the Tower Hamlets model), and they went away as good as saying they couldn't do any better and it would cost us more!

I think it is time we really made a stand on this. If Andrew Lansley is basing his decisions on the information he gets from Whizz-Kidz then he does not have the full picture and we are doing ourselves (wheelchair services) out of a job. Sorry for the rant, but this is something I feel very passionate about. These are reports sent round by an "independent" body that class Tower Hamlets as a typical service prior to Whizz-Kidz, when they quite obviously weren't. However we know that, but Jo Public and politicians who read the reports don't know that!

5. Christine Rice, Occupational Therapist, East Surrey Wheelchair Service

We would like to register our dismay at the proposed plans to tender out Paediatric Wheelchair provision.

This client group is particularly specialised and requires considerable time and skill. Our clients are often referred to us at a very early age and we develop a relationship with them and their parents over many years. The equipment provided for them is very bespoke and has to be heavily modified by experienced Therapists and Engineers. This then needs constant adjustment and adaptation. This service will not be provided by Third Party providers.

The current Paediatric Wheelchair provision is not perfect. Examples such as the provision of equipment by Whizz-Kidz in certain areas have shown that it cannot be provided better by alternative suppliers. The skill and experience you have in NHS staff is second to none. I am aware that Whizz-Kidz have promoted and evaluated their own services but if you talk to any staff or parents involved you will realise that what they do is very superficial with no ongoing responsibility or flexibility. We have several instances where parents have come back to us after provision from Whizz-Kidz and asked us to provide them with a service because they have felt the Whizz-Kidz Service to be inadequate and unsafe. Whizz-Kidz aims to provide chairs in one day. This is unrealistic if the job is done properly because individual modifications require time and expertise. Therefore what happens is clients are given equipment that is not individualised for them and therefore does not maximise their efficiency with it.

Whizz-Kidz will have the benefit of all of the funding allocated whereas we have money transferred down through many levels.

In addition, tendering out Paediatric Wheelchair Services will make the transition between children's services and adult services almost impossible because the equipment will not be able to be transferred onto the Approved Repairer contracts and clients will not get the same types of equipment because the equipment ranges are different.

I have been a Wheelchair Service Manager for Surrey for over 10 years. If you try to section off the Paediatric Service you will destroy the adult Wheelchair Service because the contracts for repairs and maintenance, Rehabilitation Engineering, and Special Seating will be unviable.

The complaints received relating to the Paediatric Service are mostly in relation to waiting list times and in relation to the limited range of equipment provided by ourselves, and this is simply because we cannot expect our repairer service to repair items not under their contract and because our budget is too tight.

The way to improve Paediatric Wheelchair Services is to put more resources into the current Service and ensure separate contracts are properly managed. At present we pay a specialised seating contract at a PCT level which is not monitored at all. This money would be better spent given to local level and allowing us the flexibility to call in the supplier most appropriate and would improve our waiting times.

What clients want is localised expertise with people that they know and trust. At present the service is disjointed and uncoordinated and it needs refinement but not by tendering it out.

6. Helen Critten-Rourke, Clinical Lead Wheelchair Therapist, Warrington Wheelchair Service; member of PMG Executive Committee

I have been quietly reading and absorbing all the information that we have been issued with over the last few weeks before writing my opinions, but this has got my goat, it is the biggest piece of rubbish I have read. We obviously need to get our commissioners and other decision makers to understand that this is not a fair representation of NHS services; unfortunately we haven't got the resources that their publicity department have. I am however particularly impressed

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that Whizz-Kidz believe that their provision of a wheelchair will prevent any back injury to a school care assistant, maybe they have invented the levitation device that I have long been wishing for!

7. Gill Searle, Physiotherapist, Swindon Wheelchair and Special Seating Service

The reports (Frontier / Whizz-Kidz) indicate a very successful service and makes interesting reading.

In Swindon Wheelchair and Special Seating Service we achieve many of the things that Whizz-Kidz do - we have a specialist paediatric OT, no waiting list, provide powered mobility for young children (as young as 2).

My comments/questions from quickly reading the 2 reports attached include:

- i) What are the urgent repair and maintenance services offered by Whizz-Kidz, as well as reassessment?
- ii) I would imagine one of the reasons wheelchair unit costs go down is because the current NHS services only provide for the more complex user, so requiring more complex chairs - if the unmet need (by the NHS) is largely with the less immobile, I would think chairs issued to them would be less costly (and more likely to achieve the 'chair in a day') - I would like to know the percentage of Whizz-Kidz chairs that require custom or complex seating and how they provide this?
- iii) Do they also provide a manual chair to children with powered chairs (as we do)?
- iv) The bottom line cost to the State in order to meet the unmet need for children as stated by Whizz-Kidz is nearly double the current cost, using the Tower Hamlets example.

8. Dawn Osborne, Wheelchair Therapist, Airedale Wheelchair Services, West Yorkshire

I can only speak for our service and what I know from meeting and talking to other wheelchair services in the Yorkshire region, but I totally disagree with many of the comments made in this report (Frontier report on the impact of Whizz-Kidz support to paediatric wheelchair services).

The long winded and inappropriate referral and assessment process identified as the nationwide NHS model is not the way our service works. What is identified as a Whizz-Kidz "innovation" is a process widely used in the NHS. The difference is that in the NHS we are not as good at publicising our success stories.

Whizz-Kidz refer to NHS Wheelchair Services as not staffed by expert paediatric therapists. This is a sweeping generalisation and not true of all services and furthermore we have direct access to the Child Development team of experienced and skilled paediatric staff.

Our service, and I know many others, have an extremely accurate, accessible and up to date stock system and, what is more, the stock and the repair service is on site so equipment can be brought to clinic from stock on the day of the appointment and supplied if suitable.

Special seating is done locally and there is no waiting list.

The sweeping derogatory statements about repair services do not apply to our service. Neither do statements about the NHS supplying heavy, outdated, old fashioned equipment.

The NHS is in danger of "throwing out the baby with the bathwater" if it listens only to Whizz-Kidz and takes Tower Hamlets as the model for the whole country.

WHEELCHAIR AND SPECIALIST SEATING SERVICES:

A Clinical Guide for Commissioners and Provider Services

Lisa Jayne Ledger BA, BSc, MSc

August 2011

DRAFT

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BACKGROUND

In December 2009 the Department of Health (DOH) set up an advisory group to review the model of wheelchair and seating services and to inform the future direction for commissioners across the NHS. The key political drivers underpinning this work are *Quality, Innovation, Productivity Prevention (QIPP)* (2009) and the White Paper *Equality and Excellence: Liberating the NHS* (July 2010) which proposed radical changes to commissioning with GPs taking more control and the setting up of a national NHS commissioning board. The advisory group identified a number of emerging themes that they believe commissioners should build into any future wheelchair model including '*a needs led approach, timely intervention, equity of provision, preventative, and encouraging innovation*'. Two pilot sites were set up in the East and South West of England and to date the common themes to arise from their work include the need for '*a single point of contact, common eligibility criteria, core assessment and partnership working across health, social care and the private sector*'. The DOH produced a document in December 2010 entitled '*Local innovations in wheelchair and seating services*' that builds on examples nationally of service improvement. The pilot sites are due to report their findings to the DOH this autumn to inform a commissioning document around future models of provision.

The rationale for this clinical paper has been brought about through concerns by the author that the multifaceted clinical nature of wheelchair service provision has not been clearly articulated nor understood to date. Both pilot sites on reporting back to a meeting at DOH in April 2011 agreed that they were struggling with the assessment element to provision and the differing clinical levels of need, from simple to mid to complex needs. It is the author's opinion that unless the clinical nature of provision is understood, the future model will be unsuccessful in meeting needs or driving efficiencies within the system. More recently the government has produced a document entitled '*Operational Guidance to the NHS: Extending Patient Choice of Provider*' (July 2011) which intends to increase choice and personalisation in NHS funded services whereby a patient should be able to choose from a list of *qualified* providers for their care. Within this paper, wheelchair services for children are listed as one of several key services to be included within this initiative. The concern within the wheelchair domain is that the parameters and measures for '*any qualified provider*' has not yet been clearly defined or scoped.

1

It is the intention of this paper to clearly articulate the clinical levels of need within wheelchair service provision, so that commissioners of services are able to understand the differing levels and that these may require a different service response. The author will also suggest that through an understanding of the clinical synergies within wheelchair provision to other services such as Tissue Viability and Specialist Community Equipment, that more integrated services may be procured and efficiencies drawn. This paper is not intended to be seen in isolation to the above political drivers around choice, partnership and personalisation, but rather it is hoped that it may enhance the understanding of the critical importance of the clinical interface in wheelchair service delivery being understood by future commissioners and evolving providers of services.

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KEY FACTS

- The wheelchair service costs approximately £125.8m a year to operate and is receiving around 184,230 referrals per annum.
- 40% of referrals are already known to the service.
- There are approximately 570,000 disabled children in England, around 100,000 of whom have a complex care need.
- In the past 10 years the prevalence of severe disability and complex needs has risen and will continue to increase due to a number of factors including increased survival of children and adults who suffer severe trauma or illness.

Figures taken from www.papworth.org.

THE CLINICAL NATURE OF WHEELCHAIR PROVISION:

Wheelchair service provision differs nationally both in terms of eligibility criteria and types/levels of response; however the clinical demands on the service remain largely the same. Wheelchair services generally provide for a long-term, permanent mobility need across the whole age spectrum from children through to adults and cover a range of clinical diagnosis including congenital and acquired disability. Over the past 10 years however, due to the increase both in the rate of service users presenting with more complex needs and the increasing severity of the need, wheelchair services have moved from simple off the shelf type input to become a specialist service incorporating wheelchairs, posture management and related tissue viability. This has placed increasing demands and challenges not least in terms of budgetary pressures, but also in terms of the necessary clinical response to manage more complex needs. The risk is that in the current financial environment, it would be easy to assume that a '*procurement led*' model could be utilised, where '*any qualified provider*' could bid for an '*equipment type contract*'. The emphasis within a '*procurement led*' model is on equipment purchased at cheaper cost and equipment delivery aspects, with little attention paid to the measurement of quality and the clinical delivery interface. This is not such an issue where the wheelchair need is simple and one off, however where the need is more complex, the individual will require regular clinical review and service delivery must be firmly grounded within the patient care pathway. In addition, with regard to the assessment process, where the need is simple, the '*trusted assessor*' will need basic competencies to prescribe the appropriate chair, however where the need is more complex the '*assessor*' will need to have specialist skills in wheelchairs, tissue viability and posture management. The focus shifts from solely the equipment solution to management of an individual's condition which may include advice, changes in care, therapy input, medical management of tone and provision of equipment.

2

Issues for Commissioning Wheelchair and Community Equipment Services:

Historically the commissioning of wheelchairs has largely been locally driven, with a 'post –code' lottery seen across the country in terms of patterns of delivery. Equally, the commissioning of wheelchairs has been within a block contract with little detail around commissioning according to level/type of response. It may be suggested that a more suitable arrangement would be whereby a pricing mechanism is used to reflect the different levels of complexity and time taken for assessment. Whatever the system, the major challenge is that the demand will continue to increase and have to be met within an ever reducing financial envelope. In order to meet this demand, there will be a requirement to create more innovative solutions to the provision of wheelchair and specialist seating services. However, in order to do this there will need to be a major shift in thinking and a movement

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away from 'silos' of provision to clinically focused integrated care pathways of provision. For example, historically, wheelchair provision has been commissioned separately; the same can be said for provision of more specialist community equipment options such as static/arm chairs and tissue viability services. Should the service be commissioned within a clinically led integrated model, then it may be suggested that the 'qualified provider' may potentially focus on different elements from simple to the more complex needs.

The use of the Kaiser Permanente Triangle for Wheelchair Provision:

The Kaiser Permanente Triangle is a well recognised population management approach that has been adopted by the government and others to providing health services for people with long term conditions. The triangle describes three main tiers of clinical need as Level One: Self-Management, Level Two: Disease Management, and Level Three: Case Management. At Level One, this describes 70-80% of patients who can be taught to 'self manage' their condition and require minimal input from health and social care professionals. At Level Two, deemed as higher risk patients, the model describes a disease management approach that must draw on current best evidence to reduce episodes of acute ill-health and unnecessary hospital admissions with individuals requiring regular monitoring of their condition. At Level Three, a Case Management approach is described for people that have multifaceted conditions and require a high degree of ongoing personalised care and multidisciplinary input.

This model is supported in the government document *Supporting People with Long Term Conditions* (2005) which presents an NHS and Social Care Model in line with the above changes, with an emphasis on independence and prevention. The model is not intended to be static but rather dynamic in the sense that at any one point in time, patients may move from one level to another and thus by focusing on a preventative approach and maintaining independence, the intention is to prevent people moving further up the triangle.

3

Winchcombe M & Ballinger C (2005) expand on the above in their paper entitled *A Competence Framework for Trusted Assessors* in response to the changes around Community Equipment Services (CES) at that time. It is useful to consider these changes to equipment services, as similarities can be drawn to Wheelchair Services. Within this model, the authors directly apply the different clinical domains of equipment provision to the three tiers of the Kaiser Permanente Triangle (See Figure 1).

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Figure 1



4

Level 1: Straight forward needs

This describes individuals who have a relatively simple need who can largely be self supporting. With regard to wheelchair provision at this level, individuals could be assessed by a '*trusted assessor*' with core basic assessment skills and competency in wheelchair prescription. Provision could then be through a number of options, including the use of personal health budgets or a voucher type option for use at any 'approved retailer' outlet. The need is likely to be one off, simplistic, and would not require review in a clinical sense; the individual could also be given general advice around related health aspects such as maintenance of healthy skin and good posture care.

However, further consideration would need to be given to who the '*trusted assessors*' are and competencies around this would need to be determined. In addition, consideration would need to be made in respect of the 'recycling' aspect and if/how the equipment would be collected and potentially re-used in the future. An example of this level of need would be an individual who only requires a wheelchair for outdoor, occasional use.

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Level 2: Specialist Support

A large proportion of wheelchair users would likely fall in this category, where assessment would need to be more specialist and clinically focused, with skills around management of a condition including tissue viability, posture care and more specialist wheelchair and seating options. Individuals at this level require regular review and inter-agency liaison and involvement within a care pathway approach. A robust clinical interface is essential at this level so that timely and appropriate intervention can occur to prevent individuals moving up the triangle. At this level, it is unlikely that equipment will be the only provision, but rather specialist advice, information, therapy, medical management to name a few of the related responses that may be indicated. Therefore, at this level the 'equipment' component cannot be separated from the clinical assessment and handover/delivery components. An example of this level would be an individual who uses their wheelchair on a full-time basis and requires a degree of postural support in the form of a contoured cushion and backrest. This type of equipment would need to be set up to the individual user's posture, lifestyle and mobility requirements, thus requiring a clinician to be involved at handover/fitting stage.

Level 3: Complex Needs

These are individuals who have highly complex requirements and are at greatest risk to their health and well being. As in level 2, the response here regarding wheelchair provision must be met within a specialist service and as part of the multi-disciplinary, interagency team. These individuals are at high risk of secondary complications due to their level of disability, such as pressure ulcers, contractures, chest infections and respiratory illness and may require an individual bespoke equipment solution. Regular review and a timely response are crucial at this level using a case-management type response. In this sense, '*any qualified provider*' would need to be clinically focused with proven expert specialist skills and competencies within the field of wheelchairs, tissue viability and posture management.

5

CONCLUSIONS

- The intention of this paper has been to describe the different clinical layers that wheelchair provision entails through use of the Kaiser Permanente Triangle.
- The author suggests the movement away from separate elements of provision to the commissioning of a more integrated care-pathway type approach which acknowledges that equipment provision is only one part of the overall necessary response.
- There are specialist clinical elements to wheelchair and equipment provision and therefore quality assurance will come from competent and adequately trained personnel and robust clinical interface.
- The further up the Kaiser Permanente Triangle the service user presents, the more necessary it becomes that the assessment and equipment fitting/handover elements sit together.

RECOMMENDATIONS

- Future commissioning of wheelchair services must take into account the different levels of clinical need and how this necessitates differing levels of provider response.
- The further up the Kaiser Permanente Triangle the service user presents, the more necessary it becomes that the assessment and equipment fitting/handover elements need to sit together.
- Future commissioning for the provision of specialist, complex needs should adopt a more integrated approach to provision, whereby an individual that presents with a posture, mobility and tissue viability need could be assessed by one team/service and the necessary equipment/provision actioned accordingly.
- There is a national need to formalise training and competencies within the field of postural management, wheelchairs and equipment against which to benchmark provision.

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Quality, Innovation, Productivity, Prevention (QIPP) (2009) DOH

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Winchcombe M & Ballinger C (2005) A Competence Framework for Trusted Assessors Assist UK, London

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6

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www.wheelchairmanagers.nhs.uk

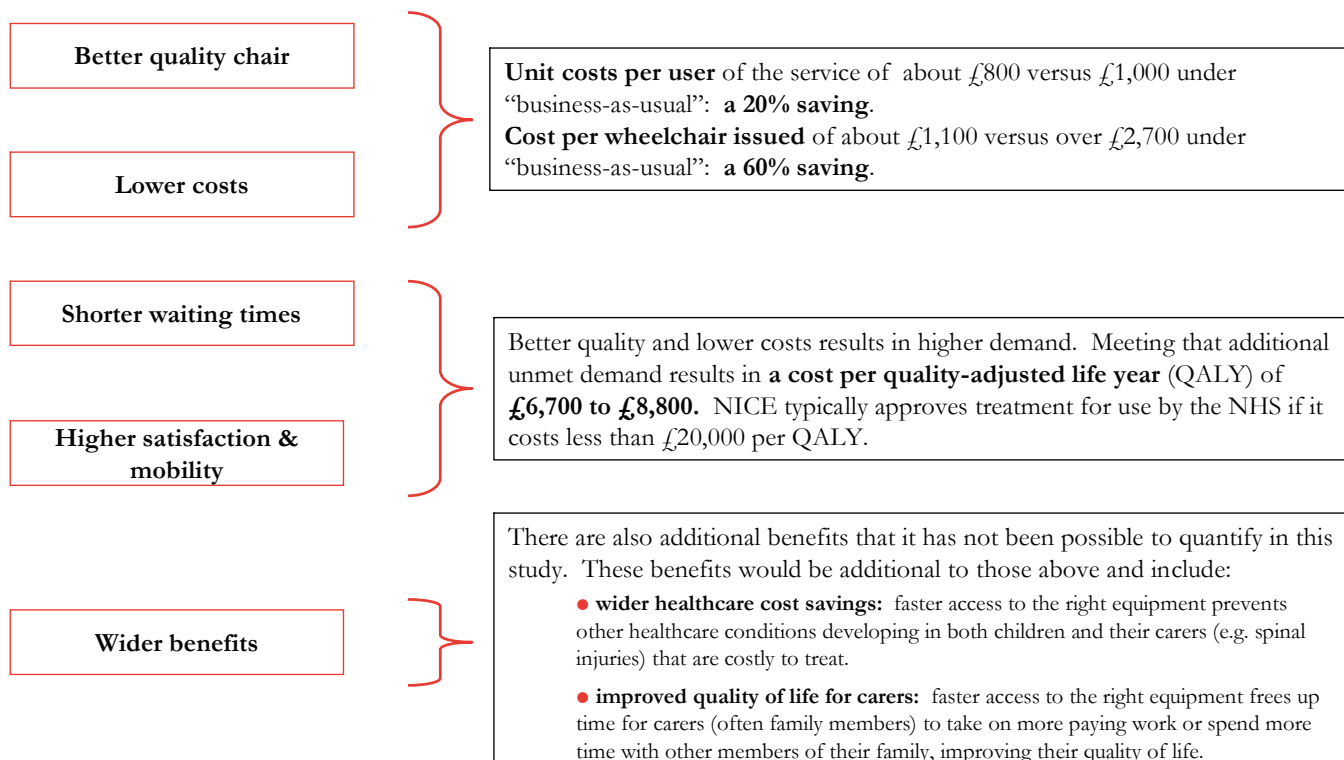
Impact of Whizz-Kidz support to Primary Care Trusts

An evaluation

October 2010

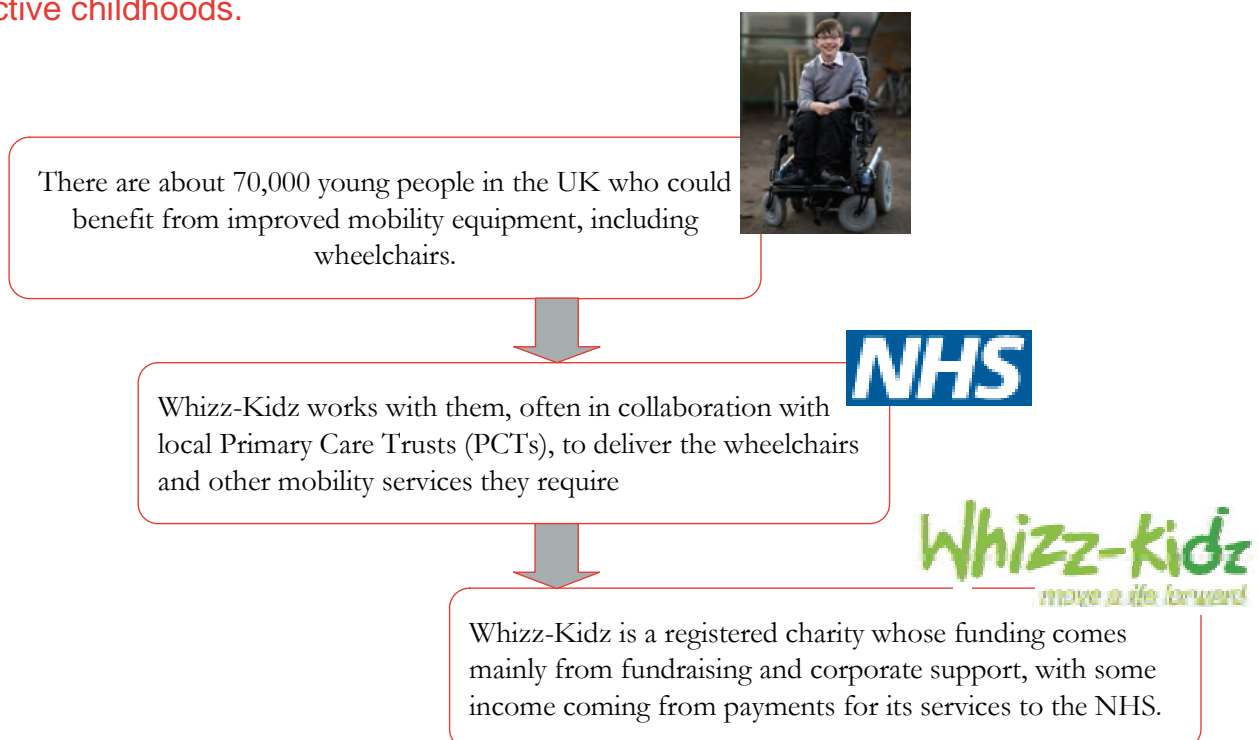
© Frontier Economics Ltd, London.

Summary: analysis of Whizz-Kidz work with PCTs to improve wheelchair provision indicates that involvement of Whizz-Kidz results in financial savings and improvements in quality of life.



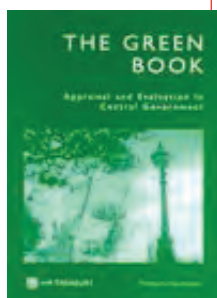
- Background
- Approach
- Results
- Overall conclusion

Whizz-Kidz provides young people with the mobility equipment they need to lead fun and active childhoods.



Whizz-Kidz asked Frontier Economics to examine the impact of the services it provides in conjunction with NHS bodies.

Our advice helps clients make better decisions. That advice blends economics with innovative thinking, hard analysis and common sense.



Government has a well developed framework for assessing the impact of its interventions. It is based on HM Treasury's Green Book: *Appraisal and Evaluation in Central Government*.



The Green Book provides a high level framework. Its application in practice depends on an understanding of the particular issue and applying the right economic tools robustly.

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Our approach develops a clear counterfactual for each type of impact, using quantitative estimates where available and qualitative results elsewhere.

The analysis is built on comparing the cost and quality of service under a:

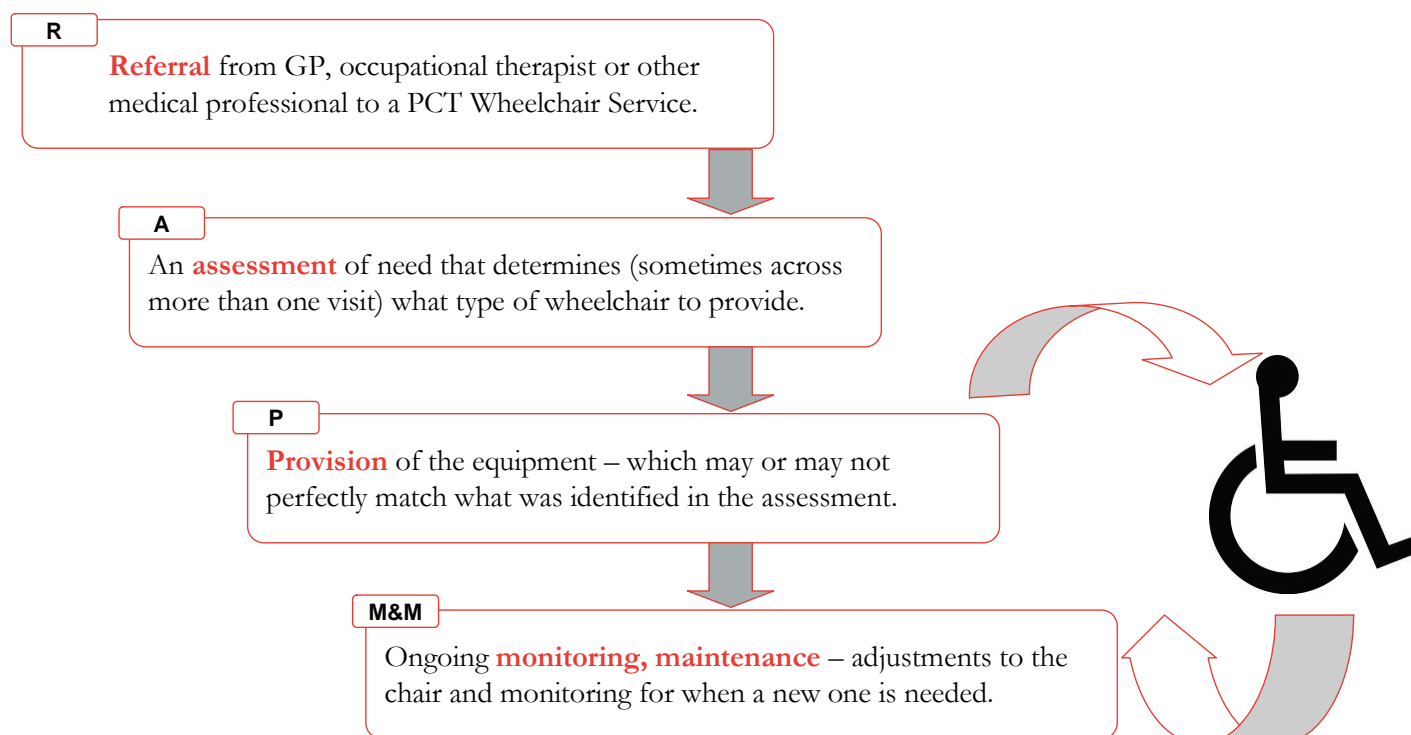
- **business-as-usual (“counterfactual”) scenario:** this scenario uses evidence available from across PCTs about the amount spent and outputs delivered by Wheelchair Services and some specific data from Tower Hamlets prior to the involvement of Whizz-Kidz
- **Whizz-Kidz (“intervention”) scenario:** this scenario draws on evidence from Whizz-Kidz involvement with Tower Hamlets and the wider roll-out of its programmes in support of Wheelchair Services.

We examine each stage of the process to deliver wheelchairs under the two scenarios. We then compare the costs and benefits in each scenario. The benefits are divided into immediate outputs (delivery of different types of wheelchairs) and longer term outcomes (avoidance of future expenditure, longer term quality of life improvements).

Our analysis focuses on healthcare issues. Where assumptions are needed we adopt a conservative approach and so are likely to underestimate the net benefit to healthcare. In addition, there is anecdotal evidence of improvements in a wider set of outcomes – including improved performance at school and subsequently improved chance of employment. We do not include these wider benefits in our analysis. For this reason alone our estimates of the net impact are likely to be a conservative estimate of the total impact on society.

This evaluation was done as a *pro bono* piece of analysis for Whizz-Kidz. It draws on the best existing data and detailed conversations with Whizz-Kidz staff and applies that evidence to a best practice framework for evaluation. There was not scope to conduct a bespoke data collection exercise or to interview other stakeholders. Anecdotal evidence and publicly available data suggests that the specific experience from which this analysis is drawn (primarily around NHS Tower Hamlets) is representative of wheelchair services more widely. This could be tested as part of further analysis.

Disabled children can access wheelchair services through a referral process that takes them to a local wheelchair service, usually supported by the local primary care trust.



Referral – Whizz-Kidz have developed a number of innovations that makes the process between referral and assessment more efficient.

Whizz-Kidz

Whizz-Kidz' collaboration with Tower Hamlets Wheelchair Service has developed a number of innovations that make the referral process faster and more efficient. They include collection of:

- as much data as possible about the child during the referral period (by phone and email), before they turn up to be fitted for a chair
- information about their entire life circumstances rather than the narrow reason for the chair (e.g. schooling, family circumstances, level of spatial awareness)

The result is that the referral process sets up the actual assessment to make “a child in a chair in a day” possible.

The Tower Hamlets collaboration suggested that appointments would be made within 1 to 4 weeks of referral, depending on the urgency of the need.

Typical PCT

The referral process is used as a way of getting the child to meet someone who can evaluate their needs.

Limited information is collected during this process, with the actual assessment appointment used to collect most of the information needed to determine the child's needs.

Source of referrals

Available data indicates that about:

- 50% of referrals to Wheelchair Services come from occupational or physio therapists
- 25% – 40% are self-referrals
- 5 – 10 % of referrals come from GPs
- balance from other sources (e.g. social workers, trusts)

Source: Whizz-Kidz surveys of PCTs

Assessment – the efficiency and effectiveness of the assessment depends on what is done leading up to the assessment, as well as who is there on the day.

Whizz-Kidz

The collection of information during the referral stage means that Whizz-Kidz have a good idea of what chair is required when the child arrives for their assessment.

The information they collect looks “at the person as a whole” and so they are able to provide a wheelchair that suits the requirements of the life they lead.

That means there is a chair that is ready for the child when they turn up, with a team on hand that can make the final adjustments to the equipment that are needed.

Whizz-Kidz will have specific paediatric expertise in the clinic on the day to make the final assessment.

Typical PCT

PCT Wheelchair Services typically use the face-to-face assessment visit to collect the information needed to decide on the appropriate chair. That often means more than one session is required to get the right chair.

Wheelchair services typically serve both adults and children so there is unlikely to be a paediatric specialist available. The reasons children need wheelchairs, and their requirements, are often different from adults, which may delay children getting the right chairs.

Provision – Whizz-Kidz process leading up to providing the chair allows them to put a “child in a chair in a day”.

Whizz-Kidz

Whizz-Kidz operate a “child in a chair in a day” programme that puts most children into chairs immediately.

The work done at the referral and assessment stages facilitates this process. It means information about the child is collected before they meet.

They undertake a full inventory of what the PCT holds in storage to understand what is currently available.

Whizz-Kidz has looked closely at the supply chain and their processes to improve how they source and provide wheelchairs. They have worked closely with wheelchair manufacturers to achieve free consignment stock and to limit the time for delivery of new chairs. They have also agreed a matrix of equipment from which therapists can prescribe. The equipment can then be adjusted at the assessment to meet the specific needs of the child.

Over the past 3 years Whizz-Kidz has worked closely with dealers and suppliers to find those offering best value for money. As a consequence they currently work with 3 preferred manufacturers, with one dealer as a strategic partner providing logistical support.

Typical PCT

PCTs tend to have a stock of wheelchairs but have poor information about what is actually in that stock. Therefore, they struggle to match it to the needs of the children and often end up ordering new chairs.

The fact that they use the assessments to collect the information about a child’s needs means they are usually unable to provide the right chair at the first appointment.

Wheelchairs are not a high priority service for PCTs and so ordering chairs often involves long delays. Furthermore, because PCTs tend to order small volumes it appears they do not get as good a price as Whizz-Kidz is able to get for a given quality chair. For example, they often source seating regionally and the chair itself locally which requires them to deal with different suppliers and coordinate deliveries.

Finally, the mixture of wheelchairs provided is different. PCTs tend to provide manual (often relatively heavy) wheelchairs. Whizz-Kidz tends to provide either light-weight manual chairs or powered chairs depending on the needs of the child.

Monitoring and maintenance – Whizz-Kidz’ ability to supply chairs that more closely match need and their system of check-ups helps to reduce future costs.

Whizz-Kidz

The Whizz-Kidz approach from referral through assessment and provision has a knock-on effect in terms of monitoring and maintenance. Their choice of chair incorporates future growth of the child reducing the need to order new chairs in the future.

They also operate a pro-active “check up” policy that reviews how the child is progressing and the chair is holding up, rather than waiting for something to break.

Their knowledge of the specific needs of children and the policy of checking up means they can better predict when a new chair will be needed and plan accordingly. That feeds back into the assessment and provision.

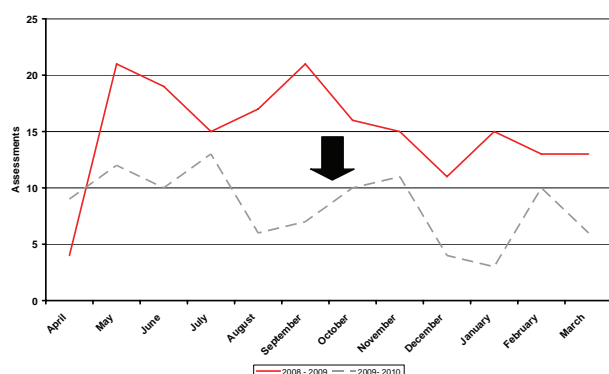
Typical PCT

PCT Wheelchair services typically will only undertake maintenance if something breaks and the child turns up at a clinic.

At that point, new parts or a new chair may have to be ordered but with no pre-warning that is likely to take time, during which the child has to continue with what they have.

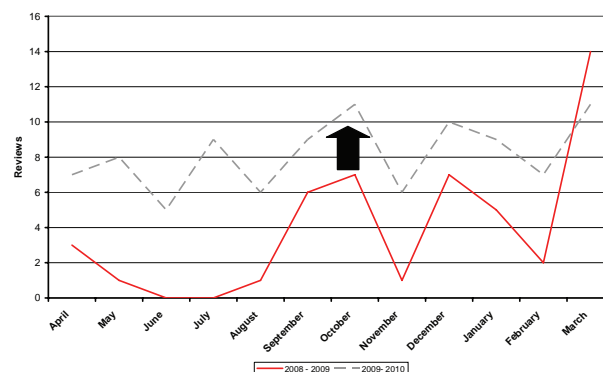
The result of Whizz-Kidz involvement is clear from data that tracks reasons for visiting the clinics...

...assessments fall in every month in the second year compared to the first as the backlog is cleared...



There are **fewer assessments** in the second year of Whizz-Kidz involvement because they have cleared the back-log of cases.

...the reviews of existing cases are higher thereafter.

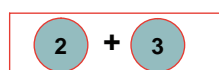
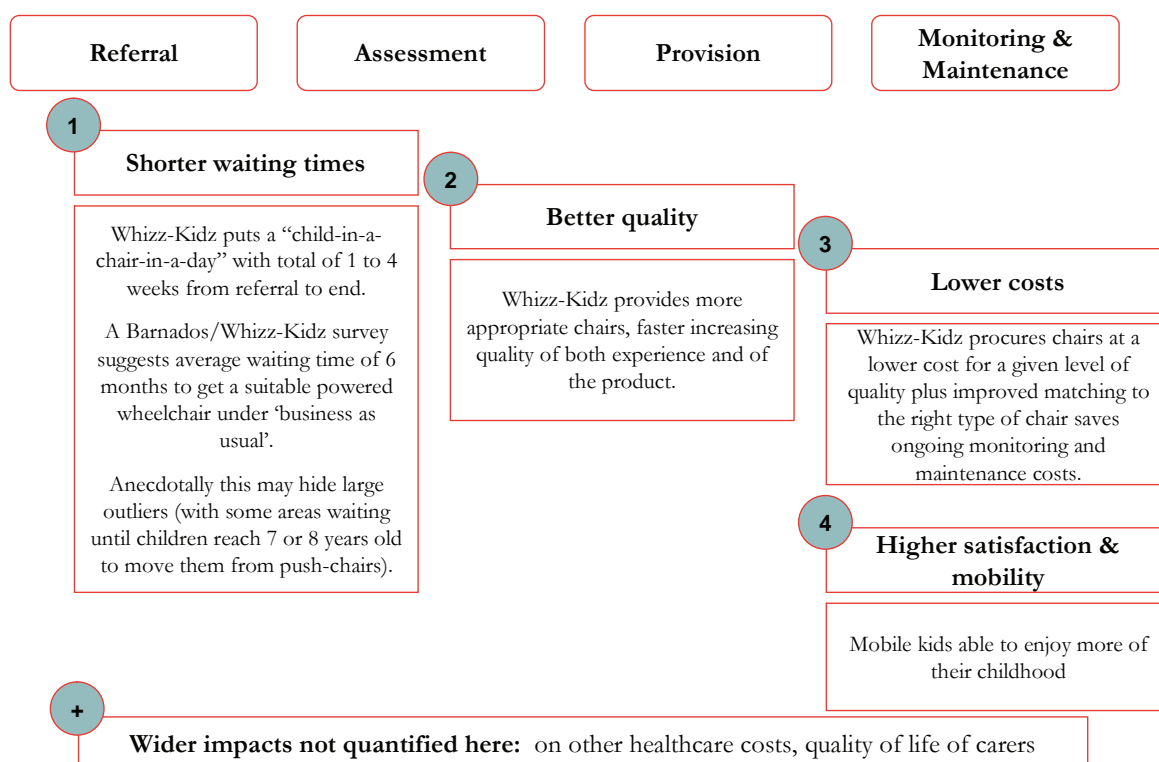


From the second year onwards there are **more reviews** for children with chairs – with Whizz-Kidz' 'check-up' process intended to improve their effectiveness.

Source: based on NHS Tower Hamlets activity data for 2008-09 and 2009-10

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This process leads to four areas where there is quantitative evidence that Whizz-Kidz out-performs the “business-as-usual” situation. Improved value for money comes from the sum of all four areas, plus additional areas that are not quantified in this study.



Better quality and lower costs result in Whizz-Kidz providing wheelchairs in excess of 20% cheaper than a typical PCT.

	Whizz-Kidz	Tower Hamlets
Annual cost	£240,000	£128,785
Staff	£90,000	£108,000
Equipment	£150,000	£20,785
Approx. annual users seen	300	123
Approx. annual wheelchairs issued	205	47
Cost per user	£800	£1,047
Cost per wheelchair issued	£1,171	£2,740

Sources: “A partnership Project between Whizz-Kidz and Tower Hamlets Primary Care Trust”, Charities Evaluation Service, January 2010; TH and WK budgets for service; “Tower Hamlets Activity Analysis”; Frontier assumptions from WK discussions about required administrative support and chairs issued before WK involvement.

The improvement in service also means Whizz-Kidz tend to supply a greater number of wheelchairs and a higher quality service and chair, which is not fully reflected in the numbers.

Shorter waiting times significantly improve quality of life – and would more than justify meeting existing “unmet demand” if NICE criteria were applied to this area.

Whizz-Kidz’ faster and better quality service means they reduce waiting lists and provide higher quality chairs. These benefits are on top of the lower costs of provision documented on the previous page. To value these benefits we compare the improvements in quality of life (using the standard Quality Adjusted Life Years – QALYs) that result from shorter waiting and better chairs with the standard threshold about society’s willingness to pay for such improvements.

	Pre Whizz Kidz	Post Whizz Kidz	Unmet need
Wheelchairs issued	47	205	158
Waiting time for a wheelchair (months)	6	1	5
Total additional waiting time Pre-Whizz Kidz (months)			790
Total additional waiting time Pre-Whizz Kidz (years)			65.8
Gain in QALY per 1 year reduction in waiting time			0.15 - 0.2
Total gain in QALYS from reduced waiting			9.9 – 13.8
Approx. annual powered wheelchairs issued (assumes Whizz Kidz serve all need)	1	21	20
QALY lost when manual supplied but powered required (per year)			0.12
Total gain in QALYs from supply of right chair			2.4
Total gain in QALYs: improved waiting time + supply of right chair			12.3 – 16.2

Sources: NHS Scotland, 2006, “*Moving Forward Review of NHS Wheelchair and Seating Services in Scotland*”; Tengs & Wallace, 2000, “*One Thousand Health Related Quality-of-Life Estimates*”, *Medical Care*; “Tower Hamlets Activity Analysis”; Barnados/Whizz-Kidz Survey of waiting times.

In Tower Hamlets, meeting unmet demand cost an extra £108,000 and **delivered 12 - 16 additional quality adjusted life years (QALYs)**. This results in a cost per QALY of £6,700 – £8,800 versus the NICE* threshold of £20,000 below which effective treatment would normally be accepted for use in the NHS.

*NICE: National Institute for Health and Clinical Excellence – the independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

These estimates are likely to be conservative because they exclude a number of wider benefits including: savings to wider healthcare budgets, improved quality of life for carers.

Without a bespoke data collection exercise, it is inevitable that some outcomes will be difficult to measure. In this case, meetings and discussions with those involved suggest that lack of comparable data in two important areas likely means that we have under-estimated the net positive impact of Whizz-Kidz’ involvement.

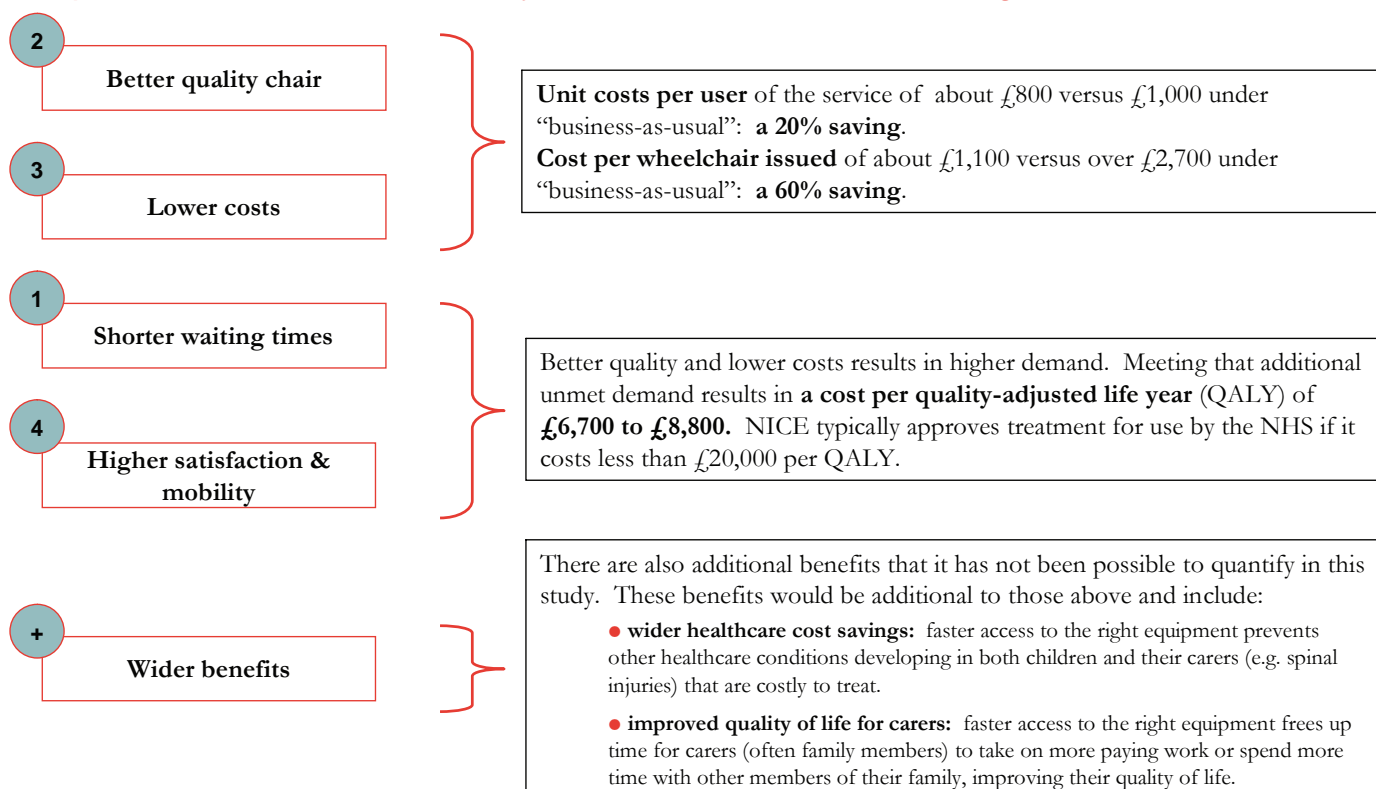
We have not been able to quantify two further positive benefits that would be additional to those that have been quantified:

- **Wider healthcare savings:** putting children into the right wheelchair quickly likely results in wider healthcare savings. Children in inappropriate wheelchairs or those waiting for a chair can develop spinal and other injuries that require subsequent, costly, NHS treatment. In addition, their carers (often their parents) can also suffer medical conditions (e.g. from having to carry and lift them more frequently than would be necessary if they had a proper chair). To the extent that these wider healthcare costs are avoided by getting children into the right chairs faster the involvement of Whizz-Kidz is linked to wider financial benefits to the NHS that free up local budgets to be spent elsewhere.
- **Impact on carers:** the greater freedom provided by getting children into the right wheelchair faster also frees up their carers, who are often family members. It improves their quality of life, allows them to take on more paying work to help support their family and devote more time to other members of their family. There has been little systematic attempt to quantify these types of impacts, despite a large qualitative literature about the impact on carers of improvements in the health of those they look after. Evidence from Dixon, Walker and Salek* suggests that for every 0.1 gain in patient quality of life, carers also gain 0.01 in their quality of life. However, the study emphasises that the result is subject to significant changes depending on the condition being considered and how quality of life is measured. It is clear that improved mobility for children would relieve carers of some responsibilities. A specific study would be required to quantify the impact for this case.

*: “*Incorporating Carer Effects into Economic Evaluation*”, *Pharmacoeconomics*, 2006: 24(1).

- Background
- Approach
- Results
- Overall conclusion

The analysis indicates that the involvement of Whizz-Kidz can offer significant improvements in value for money, as well as real financial savings.





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

**“My wheelchair
is my shoes”**

Making the case for
wheelchair reform

June 2011

Whizz-kidz
move a life forward

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Sponsored by: Whizz-Kidz

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



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.

"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

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

Lisa



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.

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

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 Hallett,
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>



From Paul Burstow MP
Minister of State for Care Services



PO00000641193

Peter Luff MP
House of Commons
Westminster
London SW1A 0AA

Richmond House
79 Whitehall
London
SW1A 2NS
Tel: 020 7210 4850

Dear Peter

27 SEP 2011

Thank you for your letter of 26 August enclosing correspondence from your constituent Mr Peter Rowell of Hedworth, Arrow End, Evesham WR11 8QU about *Operational Guidance to the NHS: extending patient choice of provider*.


I have passed your correspondence to the relevant officials in the Department, and note that you have shared Mr Rowell's letter with the All Party Parliamentary Group for Paediatric Wheelchair Reform.

The Department has engaged with a wide range of clinicians, providers, commissioners, patient groups and voluntary organisations on how best to extend patient choice of provider, and which services should be subject to choice. The engagement identified wheelchair services as an area where patients believe that increased choice of provider would lead to service improvements for users.

We agree that there are examples of best practice and high levels of positive patient experience in wheelchair services. As part of the wheelchair services programme, examples of good practice were collected and shared in *Local innovations in wheelchair and seating services*, which was published in December 2010 and can be viewed on the Department of Health's website at www.dh.gov.uk by typing the reference number '15233' into the search bar.

We do understand your constituent's concern about variable provision and the Department has carried out a review of wheelchair and specialised seating services in England, led by two regional pilot sites. A report detailing the work of the pilot sites is being prepared to provide advice for other areas wishing to improve their services.

I hope this reply is helpful.

Yours sincerely

PAUL BURSTOW

Peter Luff MP
Mid Worcestershire



HOUSE OF COMMONS
LONDON SW1A 0AA

Mr Peter Rowell
Hedworth
Arrow End
Evesham
WR11 8QU

September 29th 2011

2 Mr Rowell,

I do hope you find the enclosed letter helpful – it is clear your concerns have indeed been noted by the minster.

enc

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