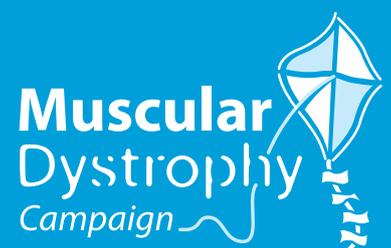




Building on the Foundations:

# Get Moving – the case for effective Wheelchair Services

June 2010



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## Foreword

Last year, the All Party Parliamentary Group for Muscular Dystrophy, which I am honoured to Chair, produced a ground-breaking report highlighting shocking gaps in services for people living with muscular dystrophy and related neuromuscular conditions: *The Walton Report*.

During the extensive inquiry that preceded the report, we heard time and time again from people who have waited for years to receive their powered wheelchair, or made to pay to get a wheelchair suitable for their complex condition.

Unfortunately, nearly a year on from the publication of *The Walton Report*, there has been little improvement. This report from the Muscular Dystrophy Campaign makes clear that the standard of care provided by NHS Wheelchair Services is simply not acceptable for people with muscle disease and their families.

The evidence shows that across England too many people are forced to wait far too long for the electric wheelchairs they need while others are denied essential features that aid independence and improve quality of life. Scandalously, patients and their families are often abandoned by the NHS and left to pay for these vital pieces of equipment themselves, at a cost of several thousand pounds.

Like me, you will be very angry to read the experiences set out in a number of the case studies – it is appalling that a young man in Plymouth has had to improvise his own head support with “a Pringles tube and some sponge”.

Not only do families deserve a better service, this will also be far more cost-efficient at this time of limited public spending. Getting the right chair at the right time can prevent the development of pressure sores, contractures or skeletal deformity. The provision of the appropriate chair can actually reduce the cost to the NHS in the long run, decreasing the need for potentially expensive operations and costly inpatient episodes.<sup>1</sup>

I hope that NHS decision-makers decide to work alongside people living with muscle disease, the Muscular Dystrophy Campaign, clinicians and health professionals to ensure that all adults and children living with a neuromuscular condition, and in need of an electric wheelchair, experience a far better service in the future.

I am passionate about this issue as I have spent a lifetime in a family that has been devastated by muscle disease. My brother and sister, who were affected by a form of muscular dystrophy, had lifelong disabilities but not very long lives.

I am proud to put my name to this report and, together with people living with muscle disease and their families, I am calling on the new Government to take urgent action to fix this failing service.

**Dave Anderson, MP  
for Blaydon, and  
Chair of the All Party  
Parliamentary Group  
for Muscular Dystrophy**



# Executive Summary and recommendations

**Children and adults with muscle disease in England are forced to wait weeks, months and sometimes years to receive the wheelchairs that are essential for their health and quality of life.**

**A lack of funding and understanding of neuromuscular conditions among NHS decision-makers often means that people with muscular dystrophy are denied the wheelchair that best suits their needs, or are forced to pay out of their own pocket.**

**Despite a commitment to provide and maintain wheelchairs in a 'responsive, rapid and effective manner within the stated key aims of Wheelchair Services'<sup>2</sup> the problems with the services are being allowed to continue.**

**The Muscular Dystrophy Campaign is calling on the new Government to act on the following recommendations.**

1. A short-life review group, led by the Department of Health, to be established to address the failings of Wheelchair Services.
2. The review group should examine the evidence set out in this report for the savings and improvements made through new service models, and ensure they are implemented nationally (see appendices)
3. A national target for waiting times for wheelchairs should be set at a maximum of 18 weeks from initial referral to delivery of the chair.
4. An adequate ring-fenced budget to be established for electric wheelchairs in each Primary Care Trust (PCT) and Specialised Commissioning Group (SCG).
5. Uniform eligibility criteria and a national consensus to be developed regarding the features and equipment that should be provided by the NHS.
6. PCTs to pay for the cost of maintaining all wheelchairs, including those that have been modified or privately funded, and for maintenance to be carried out quickly and efficiently.
7. The pilot scheme *Ending the wheelchair postcode lottery* should be carried out as soon as possible, and the findings must be reported and decisively acted upon.
8. Full implementation of Definition no. 5 of the NHS Specialised Services National Definitions Set with a named lead for specialist equipment in each SCG.
9. The above recommendations to form a national strategy for wheelchair provision to reduce waiting times and improve access, bringing an end to the current postcode lottery.

## Neuromuscular conditions and the Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign supports the 70,000 people across the UK living with more than 60 different types of neuromuscular condition. These are rare and very rare conditions that can be genetic or acquired, and can present in childhood or adult life.

Neuromuscular conditions cause muscle weakness or wasting. They are multi-system disorders that require complex long-term care. There are currently no known cures or treatments. Without multidisciplinary care, most patients experience a reduction in quality of life and, for some conditions, shortened life expectancy.

For many people with a neuromuscular condition a powered wheelchair is vital for independence and quality of life, and is also essential to help manage any physical complications. Access to the right equipment at the right time can also help to slow the progression of the condition and improve prognosis.

# Failings of Wheelchair Services

**The research carried out by the Muscular Dystrophy Campaign shows that many wheelchair and equipment services are not meeting the needs of individuals with neuromuscular conditions for two key reasons.**

## **1) A lack of knowledge in health services**

To ensure that people with neuromuscular conditions receive the correct wheelchair it is essential that detailed patient assessments are made. These assessments require a greater level of knowledge and expertise than is often available in local wheelchair services.

A Freedom of Information request by the Muscular Dystrophy Campaign has revealed that many PCTs do not collaborate to provide specialist wheelchair services, instead dealing with the issue on a local level. By doing this, people with specialist wheelchair needs must compete for equipment with patients who have far simpler needs, such as a patient with a leg fracture, denying them the attention their condition demands.

Wheelchair Services often appears to fail to take into account the degenerative nature of neuromuscular conditions. The continual weakening of muscles and development of spinal problems associated with many conditions can greatly affect the type of equipment required from one year to the next. Features such as supportive seating and tilt-in-space wheelchairs can delay the development of spinal deformities, but these are often unavailable or not provided in time to avoid the devastating physical consequences, further emphasising the need for detailed and continual review of appropriate equipment.<sup>3</sup>

Evidence shows that access to the correct powered wheelchair not only significantly improves mobility but also prevents deformity<sup>4</sup> and reduces pain and discomfort.<sup>5</sup> As access to the right equipment reduces the risk of developing complications including scoliosis and contractures, the need for extended hospital stays and expensive treatment is further decreased.

There is also a substantial body of research illustrating the benefits of good equipment on quality of life.<sup>6</sup>

### **Why is having the right wheelchair at the right time so important for people with muscular dystrophy?**

Children with muscular dystrophy can rapidly deteriorate and this, combined with growth, leads to a constant change in needs. Delays in assessment and provision of appropriate wheelchairs can be detrimental to the health and well-being of the child.

Postural support within wheelchairs is vital to avoid muscle fatigue for both children and adults. Contoured back supports allow an individual to retain an upright position and help to prevent spinal deformities developing.

Early provision of wheelchairs with tilt-in-space and recline facilities is thought to help reduce the impact of gravity on scoliosis, while supportive seating can also prevent the development of contractures in the hip, knee, ankle and foot.

### **Getting the right equipment at the right time is key to the ongoing health and well-being of people with neuromuscular conditions.**

Neuromuscular conditions are often extremely debilitating, with many people becoming dependent on others for support with everyday activities. Provision of the correct wheelchair and seating system can help to alleviate dependency, improving quality of life and mental wellbeing.

The numerous benefits of powered wheelchairs mean that people with neuromuscular conditions can live full and independent lives, engaging in employment, education and a wide range of everyday activities. The ability to participate in exercise and sports, like wheelchair football, plays an important role in the physical and emotional development of disabled children.<sup>7</sup> By reducing social isolation in this way, wheelchairs can decrease the likelihood of depression.<sup>8</sup>

**Wendy Hughes from Devon, who has a son with myotubular myopathy shared her experience of Wheelchair Services:**

*"I have never been more angry or upset about a seemingly hopeless situation. Zak's fight for independence has been an upward battle and completely frustrating, demoralising and hopeless for the whole family – we have all been affected by it. We feel like we are constantly fighting a losing battle and we are weary of it after 13 years."*

## 2) Funding

Adequate funding is essential to ensure the provision of appropriate equipment for people with neuromuscular conditions. The current situation in England is unacceptable, with the Department of Health (DH) admitting that: 'England spends less on wheelchairs than comparator countries.'<sup>9</sup>

Wheelchair spending in England is not ring-fenced (this was introduced in 1996, but only for a period of four years). The DH states: 'Faced with immediate budgetary pressures, the long-term and wider benefits of providing an appropriate wheelchair are often lost in favour of what appear to be short-term financial savings.'<sup>10</sup> Funding cuts can also affect the level of training available to staff working in Wheelchair Services.

**When people with neuromuscular conditions are unable to get the equipment they so desperately need, they must either approach a charity, fund the equipment themselves or, too often, simply go without.**

The cost benefits of increased investment in Wheelchair Services were acknowledged by the previous Government. A joint report by the Treasury and Department for Education and Skills in 2007 noted that 'early provision of equipment or wheelchair[s]... may prevent the development of pressure sores, contractures or skeletal deformity'. The report acknowledged that the

provision of the appropriate equipment can reduce the cost to the NHS in the long run, minimising the need for 'potentially expensive operations' and expensive 'inpatient episodes'.<sup>11</sup>

### Principal funding reasons why equipment is often denied to those in need:

- **Lack of awareness:** Wheelchair Services may not have the specialist knowledge needed for these complex conditions.
- **Limited funding available:** Wheelchair Services may have been allocated a limited budget by PCTs.
- **Equipment is restricted:** Wheelchair Services may have a limited list of equipment it is willing to fund.
- **Equipment rationing:** Equipment may be limited to one piece per patient.
- **Excessively strict criteria:** The provision of equipment is often based on strict assessment criteria rather than actual need.

## Key findings

A year-long investigation by the Muscular Dystrophy Campaign based on results of Freedom of Information requests has shown that children in England with a neuromuscular condition wait an average of 20 weeks to receive a powered wheelchair. For adults, the average wait was 18 weeks.<sup>12</sup>

These figures hide drastic regional variations, creating an unequal postcode lottery system. This is allowed to continue by the lack of a clear national guideline that sets out appropriate timescales from first consultation to eventual wheelchair provision.

### For children with a neuromuscular condition in need of a powered wheelchair:

- Children in England with neuromuscular conditions are forced to wait an average of 20 weeks to receive a powered wheelchair from the NHS.
  - In 15 PCTs the average wait is longer than six months.
  - Shockingly, in two PCTs, the average wait is more than a year.
- There can be up to 11 months difference in waiting times for disabled children living just four miles apart.
- Fifty percent of PCTs will not fund the full cost of a powered wheelchair for a disabled child, only funding the cost up to a certain level. This level does not cover essential features such as risers as they are often falsely considered to be related to lifestyle rather than clinical need.
- Almost all PCTs and Health Boards state that the average cost of a powered wheelchair for a child is £2,000. However, the grant-giving organisation the Joseph Patrick Trust calculates the true cost with essential features up to £17,500.

### The situation for adults with neuromuscular conditions is just as bad – and often worse:

- Adults in Bolton wait between two and a half and 12 weeks compared to those living in Cumbria who are forced to wait an average of 60 weeks.

One patient has a wheelchair that is ten years old and 'falling apart'. She has been trying to change the chair for over a year. Local Wheelchair Services told her that it had found a new chair for her to try, but they keep sending her the same unsuitable wheelchair, which she then has to get sent back:

*"I have had no chance of trying another chair. I need a different type and shape of chair now, no-one is listening and it's soul destroying."*

- Adults in Bristol are forced to wait an average of 44 weeks.
- The postcode lottery of NHS equipment provision is further highlighted by a difference in waiting times for wheelchairs of up to seven months between Islington (two months) and Croydon (nine months), just 12 miles apart.

**A survey of 100 patients conducted by the Muscular Dystrophy Campaign in 2010 suggested that the real average waiting time for both adults and children affected by neuromuscular conditions is now 10 months.**

As well as having a detrimental effect on the health, mental wellbeing and finances of people with neuromuscular conditions, these severe delays lead to a further burden on the NHS as subsequent health problems develop requiring treatment.

### Why can some areas provide equipment so much more efficiently than other PCTs across the country?

- Almost 90% of PCTs claim to pay for the full cost of adult wheelchairs up to the level of assessed clinical need; a level that does not generally cover features that are vital to the independence and comfort of many individuals:
  - Three quarters of PCTs do not provide a riser function that allows the user to elevate their seat to be at eye level with their peers.

- 90% of the PCTs refuse to provide the sit-to-stand feature that is crucial for muscle exercise and preventing pressure sores.
- Only 3% of PCTs offer riser, sit-to-stand and tilt-in-space (which allow users to relieve pressure on their bottom and legs, helping to prevent pressure sores), features to adult wheelchair users.
- The majority of PCTs state that the average cost of a powered wheelchair for an adult is around £2,000. Central Lancashire offered the lowest estimate (£1,700), which is in contrast to Harrow's average estimate of £5,000:
  - The Joseph Patrick Trust calculates that the real average cost of a powered wheelchair is around £17,500, far in excess of the average amount spent by even the most generous PCTs.
  - £2,000 buys only the most basic powered wheelchair, meaning that individuals must either do without the features that they need or rely on the support of charities or their own funds to acquire them.

**The Muscular Dystrophy Campaign's 2008 patient survey *State of the Nation* revealed that more than a third of people with muscle disease receive no funding for their wheelchair from the NHS. The Muscular Dystrophy Campaign believes that this is due to a combination of essential features not falling under the narrow definition of clinical need and long waiting times forcing people to look for private funding to get the right wheelchair when they need it.**

**Half of patients have experienced delays or difficulties in receiving the appropriate chair.**

**One in three people rated the service received for assistance in the upkeep of their chair as either poor or very poor.**

**Jill Brown, 68, from Wiltshire has progressive neuropathic myopathy, has been waiting twelve years for the powered wheelchair that she needs. Six weeks ago she finally received her wheelchair. Sadly this chair still does not meet all her needs as she is unable to use the chair on rough ground, meaning that she has to make do with her old outdoor chair in the park where she exercises her dog for the disabled.**

Six weeks after finally receiving the wheelchair she is also still waiting for some adaptations to be completed. She says:

*"It has been a real fight to get my chair."*

We believe that people shouldn't have to fight to get the equipment they need.

## Wheelchair maintenance

The Muscular Dystrophy Campaign is concerned that many Wheelchair Services refuse to pay for the ongoing maintenance of wheelchairs that have been modified or bought privately. As the NHS has saved money by not paying for modifications or wheelchairs, we believe it should cover the ongoing cost for maintenance.

The Muscular Dystrophy Campaign has funded more than 500 wheelchairs for children over the past year and is concerned that the NHS will refuse to cover the cost of maintaining these chairs, leaving patients and their families saddled with a great expense.

If a wheelchair needs repairing, users are often told that there is a lengthy wait for the repairs, even if it is an NHS chair.

**Wheelchair maintenance should be treated as a matter of urgency, especially where the individual is reliant upon the equipment for health reasons as well as quality of life and independence.**

## What is the national policy on wheelchair services?

Provision of specialist equipment for people with neuromuscular conditions is covered by the Department of Health's Specialised Services National Definitions Set. These definitions outline what people with rare conditions have a right to expect from NHS services. Wheelchairs and other specialised equipment are covered under Definition no. 5.

### **Definition no. 5 of the Specialised Services National Definition Set outlines standards for 'The Assessment and Provision of Equipment for People with Complex Physical Disabilities'.**

'Specialist assessment, provision of equipment and training should be delivered as part of a total package of care, to ensure that service users are provided with the most appropriate equipment and are enabled to use it to optimal advantage.

'The other aspect common to many of these services is the long-term nature of the provision. Users will often need provision throughout their lifetime. Commissioning arrangements should therefore provide the resources to review and maintain equipment in order to accommodate the changing needs of this client group.'<sup>13</sup>

**Brian Deehan, the chair of the Yorkshire and Humber Muscle Group**, comments that, when a lift breaks down in a shop or office, the lift company is obliged to respond quickly and will almost always attend between one and three hours from the original callout.

It is not just private firms that have such call out contracts; this is also the case when the lift is in a publicly-funded building. He points out that

*"If the public purse can afford that then surely it can afford to pay for urgent repairs to wheelchairs for those users whose only other alternative is to stay in bed to the detriment of their health and quality of life!"*

### **James Ledbrook lives in Western-Super-Mare and has Becker muscular dystrophy:**

James is soon to undergo a major operation on his foot as a result of his condition. After the operation he will require a wheelchair for a few months as he will be unable to use the crutches that he usually relies on for mobility. Despite the fact that he will need the wheelchair as a result of an essential operation he will not be eligible for an NHS wheelchair as he may not require it for longer than six months.

James previously had a similar operation on his other foot and his brother, who also has Becker muscular dystrophy, was forced to drive him on the thirty-mile round trip to the nearest Red Cross shop to hire a wheelchair at a cost. This was made even more difficult and inconvenient by the fact that the shop was inaccessible and located on a busy main road with no parking. James's brother rightly points out that

*"surely the NHS should be able to supply him with a wheelchair while his foot heals".*



The Muscular Dystrophy Campaign has discovered evidence that the NHS Definition for wheelchairs is yet to be fully implemented, if at all, across the ten SCGs.

A telephone survey conducted by the Muscular Dystrophy Campaign uncovered very poor levels of knowledge and understanding about NHS Definition no. 5 within each SCG.

When our researcher rang each of the SCGs to ask about NHS Definition no.5 the response was similar in each case. The researcher was passed around different departments, none of who seemed to have any knowledge of the Definition, who the lead was or how it was dealt with.

Responses included:

- ‘Specialist equipment is commissioned by the PCTs.’
- ‘We don’t do wheelchairs.’
- Lack of knowledge of who was responsible for specialist equipment.

This survey demonstrates that there is an alarming lack of awareness among the SCGs about Definition no. 5, suggesting that it has not been fully implemented. We are calling on each SCG to implement Definition no. 5 as part of their review of neuromuscular services, and to nominate a named lead for specialist equipment.

NHS wheelchairs are provided by the 151 PCTs, each with their own patterns of working and their own criteria. The previous Government stated its belief that PCTs are ‘best placed to determine which type of wheelchair is provided, after detailed clinical consultation and patient evaluation.’<sup>14</sup>

As highlighted previously, patient assessments for wheelchair provision are often based on a strict and inflexible interpretation of ‘clinical’ needs. As a result, the basic equipment provided often does not consider integral aspects of people’s lives such as independence,

employment or education. The Government itself in 2007 noted that ‘provision may focus too heavily on clinical need and fail to take into account the impact of independent mobility on social, development and educational attainment, or on family’s preference.’<sup>15</sup>

This policy has led to the DH, while acknowledging patient concerns, consistently responding to Parliamentary Questions about wheelchair provision by maintaining that wheelchair provision is dealt with locally and is the responsibility of the PCTs, thus denying responsibility and sidestepping the issue.<sup>16</sup>

This regionalised structure, along with the aforementioned lack of cooperative working between PCTs, has resulted in a wide variation in the quality and nature of the services available to patients. Worryingly, a number of professionals working in the area of equipment provision are not even aware of the guidelines that do exist, such as the NHS Specialised Services National Definitions.

The National Service Frameworks – long term strategies for improving specific areas of care – also lay out blueprints for the way health and social care services should support those with specialist requirements.

The National Service Framework for Children, Young People and Maternity Services sets standards for services for disabled children and their families. It requires that all disabled children have access to any equipment required and that the commissioning of services is integrated across health, social care and education.

The National Service Framework for Long Term Conditions states:

‘People with long-term neurological conditions are to receive timely, appropriate assistive technology, equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.’<sup>17</sup>

**Karen Duckmanton, aged 31 from Essex, shared her personal her experiences of Wheelchair Services:**

*"I am a manifesting carrier of Duchenne muscular dystrophy and, up until 2003, I was able to walk around indoors and a little outdoors. I would use my wheelchair outdoors for long distances and had no problems with Wheelchair Services.*

*In December 2003 I broke my leg and was in hospital for five weeks. I informed my local Wheelchair Services (which is Mid Essex) of this and requested a leg rest from them so that I could use my wheelchair – it took them three weeks to get one to me.*

*When I left hospital in February 2004 I requested a reassessment and was seen in June 2004 – it took them six months to sort the wheelchair out for me. I was given a manual chair that had been reconditioned and had originally been given to someone with long legs (I have short legs), so was not even made for my specifications even though I had been assessed and my measurements taken.*

*At that time I asked whether I could have an assessment for a powered wheelchair as I was no longer able to walk and had weak arm muscles (this is still the case) – I was advised that there was an 18-month waiting list, but that I would not qualify for one anyway.*



*The reason given for not qualifying was that I could push myself. However, I was never assessed as to how far I could push myself or how much effort it took and I was never asked whether I could push myself when I am outside, which I cannot. This meant that I had to rely on other people to push me when I am outside and had no independence.*

*In September 2005 I ended up buying my own powered wheelchair, which my parents paid for with their credit card and then I paid them a monthly amount until it was paid for – the cost of the chair was £3,300.*

*In early 2008 I wrote to Wheelchair Services to ask for a reassessment as the manual wheelchair I had was no longer meeting my needs. I was seen more than six months later having kept calling them to ask when I was likely to be seen. I got the impression that their opinion was; 'you've got a wheelchair what's your problem?'*

*When I was reassessed I asked about the voucher scheme as I wanted to get a wheelchair that had powered wheels added to a manual chair. I was talked out of going on the voucher scheme as they advised that I would have to pay for my own repairs and also that I would have problems getting the specialist seat I have as they had to go to a specialist company to get it and it would cost me more money.*

*Even though I could still not walk and had weak arm muscles, I was told that I only qualified for a manual wheelchair. I then asked whether I could add the powered wheels (which give you three times the effort you put in) to the chair and was told that as it was the property of Wheelchair Services I could not. After three months of letters and phone calls they finally agreed that I could - so I bought them (it cost me £3,700) but it was worth it as it means I have more independence when going outdoors as I can push myself where I want to go."*

### Does the 18 week target apply?

In December 2008, the previous Government set a maximum 18 week target from patient referral to treatment.<sup>18</sup> There is some confusion around whether this target applies to the provision of wheelchairs. Phil Hope, the former Minister for Care Services, stated that 'wheelchairs are classified as medical devices and are covered by the 18 weeks referral to treatment commitment'.<sup>19</sup>

When the Muscular Dystrophy Campaign rang the DH to ask if there is a national target for waiting times for wheelchairs we were informed that such a target did not currently exist and were directed to the document entitled *Healthcare Standards for Wheelchair Services under the NHS*.<sup>20</sup> This report outlines a range of minimum response times for certain stages of the process, such as 'from receipt of referral to assessment' (15 working days) and 'from prescription to delivery' (30 to 60 working days). Despite this, it sets no benchmark for waiting times for the entire process from initial referral to the delivery of the chair. It is clear that if a target for waiting times for wheelchairs does exist there is a great deal of confusion around it and these targets are not being met.

**A clear, comprehensive target would compel PCTs to address excessive waiting times and bring an end to the current postcode lottery system.**

One lady, 33, from Newcastle, who has congenital muscular dystrophy, waited just one week to get her wheelchair, the full cost of which was funded by the NHS, and she was very happy with the service that she received.

It can be done. Wheelchairs can be provided in a timely manner with minimal stress to the individual. Why isn't this always the case?

### Policy context

A number of reports published in recent years have highlighted the difficulties experienced by patients trying to access wheelchairs. The Audit Commission's 2000 report *Fully Equipped*<sup>21</sup> found that the standard of commissioning of equipment services was exceptionally weak, highlighting wide variations in waiting times and eligibility as areas of particular concern. These concerns have also been highlighted in the joint report between Whizz-kidz and Barnado's, *Don't push me around! Disabled children's experiences of wheelchair services in the UK*, and the DH's 2004 report entitled *Improving services for wheelchair users and carers – Good Practice Guide*.

Within the evaluation of the introduction of the electric powered indoor/outdoor (EPIOC) chair scheme in 2000, among the concerns of various wheelchair services was the lack of national eligibility criteria for EPIOCs, stating that such a criteria 'would have been both more equitable and efficient'<sup>22</sup> The DH admitted in 2007 that: 'this produces profound inconsistencies which need to be addressed.'<sup>23</sup>

Despite a number of reviews by government departments, such as the follow up to the *Fully Equipped Report: Fully Equipped 2002 - Assisting Independence*<sup>24</sup>, the DH's 2004 Good Practice Guide for Wheelchair Services<sup>25</sup> and the joint report by the Treasury and Department for Education and Skills, *Aiming High for Disabled Children*, published in 2007<sup>26</sup>, few of the recommendations of these reviews and strategies have been implemented.

In 2004, the Prime Minister's Strategy Unit highlighted the proven benefits of 'appropriate equipment and adaptations' for independence, reducing reliance on personal assistance and preventing and reducing health problems.<sup>27</sup> However, this is not happening in practice.

Furthermore, the wheelchair component of the 2006 review *Transforming Community Equipment and Wheelchair Services*, was never published.

### **Transforming community equipment and Wheelchair Services**

In June 2006, the Government launched the *Transforming Community Equipment and Wheelchair Services* programme. The aim of this programme was to develop with stakeholders a 'radical new model' for delivery of community equipment and wheelchair services in England. By March 2007 the community equipment consultation process had resulted in the production of a new conceptual model for service provision. The wheelchair services element of the review stalled however. The DH decided that further evidence was necessary before recommendations for action could be made. Unfortunately, the former Health Minister's request for a report in autumn 2007 was never completed.

In January 2009, the Health Minister at the time, Ivan Lewis, told MPs that the business case to support the recommended way forward 'is currently being finalised'. The report is still yet to materialise.

In March 2010 the Muscular Dystrophy Campaign contacted the DH and was informed that the process was ongoing. The DH was unable to specify what stage had been reached in the development of the report or give an estimate as to when the review may be completed and eventually published.

The wait for the 'radical new model' for wheelchair services does not appear to have any end in sight.

### **Jennifer McLarnon, an occupational therapist from Plymouth said:**

*"I have a client with congenital muscular dystrophy and he has the most complex seating needs I have encountered. While I appreciate this is a challenge for Wheelchair Services, this young man has been left to construct his own 'homemade' head support with a Pringles tube and some sponge as they were unable to meet his needs."*

One lady from Bolton who has a young son with Duchenne muscular dystrophy commented:

*"Wheelchair Services are inept and treat people as a number."*

A three-year-old child with a neuromuscular condition and osteoporosis has been provided with a wheelchair branded 'lethal' by his mother. As well as having anti-tip bars that protude so far from the back of the chair that his parents are unable to push him without banging their legs, the chair is also very unstable. On a number of occasions the chair has tipped forward after hitting small objects and has even tipped all the way over on one occasion, falling on top of him and risking serious injury.<sup>28</sup>

## Next steps

In the nine recommendations set out in this report we are calling on the Government to take the action necessary to address the failings of Wheelchair Services.

On the 19 March 2010 Phil Hope, then Care Services Minister, announced a new large-scale pilot project in the east of England and the south west of England entitled *Action to end the wheelchair postcode lottery*.

The scheme aims to develop a consistent approach to equipment entitlement criteria across the country and focuses on delivering services in a 'timely' manner.

The pilot also aims to encourage PCTs to work together, combining spending power to get the best prices from wheelchair suppliers and integrating wheelchair support with other services.

### Phil Hope said:

*"Not having the right equipment to get about easily can restrict freedom, isolate and prevent an individual from fully contributing to society. That's not right. That's why we are developing a national entitlement standard for Wheelchair Services.*

*"By combining local NHS spending power and assessing people's needs in the same way, wherever they live, we can provide better quality services and help people get on with their lives."*

### Wheelchair users need action now

We are concerned that the latest commitment to review and reform the way that wheelchairs are commissioned across the country will meet the same fate as its predecessor, the *Transforming Community Equipment and Wheelchair Services* programme (2006), of which the wheelchair component has never been published.

The Muscular Dystrophy Campaign welcomes this pilot scheme and urges the new Government shares our concerns regarding the provision of wheelchairs along with the need for urgent action as set out in this report.

Add your weight to the campaign for better wheelchair provision. You can contact the Campaigns Team at the Muscular Dystrophy Campaign on **020 7803 4847** or **campaigns@muscular-dystrophy.org**

We are taking the fight for better Wheelchair Services to the devolved countries - if you live in Scotland, Wales or Northern Ireland get in touch to join the campaign.

# Appendices

## Appendix 1: The Whizz-Kidz Model – lessons to be understood and shared widely

### Whizz-Kidz: Working in partnership with the NHS to deliver world class Wheelchair Services

Whizz-Kidz is a national charity and the biggest provider of mobility equipment for disabled children and young people outside the NHS.

The charity is working with partners in the NHS to pioneer a new approach to wheelchair provision, based on efficient use of limited resources, smarter procurement practices and standards of care that address the holistic needs of every young disabled person.

Whizz-Kidz employs a team of paediatric mobility therapists and assess young people for equipment looking at how it may help them to gain independence at school, at home and socially. The young people supported by the charity are also offered opportunities to take part in wheelchair skills training to help them use the equipment safely and to maximise their independence.

In 2007 the charity began to work collaboratively with Tower Hamlets PCT to deliver a better and more effective wheelchair service for local young people. By bringing together resources, expertise and introducing new ways of working the award-winning partnership has virtually eradicated the waiting list for mobility equipment. It has also increased the focus on early years provision, helping children as young as two years of age gain access to powered mobility, achieved 100% satisfaction rates with equipment and transformed the lives of hundreds of disabled children and their families.

The success of the Tower Hamlets service was recognised in the Government's Child Health Strategy as a new partnership between the London Strategic Health Authority and Whizz-Kidz was announced. This partnership was set up to look at how the model of delivery for children's Wheelchair Services in Tower Hamlets could be implemented across the capital.

The charity has since established a similar partnership with outer North East London Community Services and delivers wheelchair services within the NHS for

young people in Barking and Dagenham, Havering and Brentwood. At the time of writing, the charity is implementing several other partnerships with PCTs in London and further afield which it expects to launch in summer 2010.

Whizz-Kidz has also been working with expert buyers from corporate partner Tesco to develop a new procurement strategy for the purchase and supply of mobility equipment. This has helped them to secure significant discounts on mobility equipment orders and allowed Whizz-Kidz and its NHS partners to invest savings back into the service.

The charity has also worked closely with consultancy firm Accenture to achieve an ambition it calls 'child in a chair in a day'. It is extremely frustrating for children to try out new equipment at an assessment yet have to wait weeks or months for their own equipment to be delivered. The charity has completely reshaped its processes for both its mainstream provision and work within the NHS and, as a result, increasing numbers of disabled children seen by Whizz-Kidz therapists are taking home their equipment on the day of the assessment.

## **Appendix 2: Bradford Wheelchair Service: An example of what can be achieved by the NHS**

Sue Manning, a Neuromuscular Care Advisor for Leeds, has identified Bradford Wheelchair Services as an example of a service that goes to exceptional lengths to ensure that individuals get the wheelchair that best suits their needs. She has been working in partnership and arranging joint funding with Bradford Wheelchair Services for 14 years, and praises their imaginative and open-minded approach to wheelchair provision.

Bradford Wheelchair Services is faced with the same financial pressures as other areas so where they do not provide funding for wheelchair features; they have looked to funding partnerships as a solution. Bradford Wheelchair Services carries out the assessments and fully funds up to the level of assessed clinical need with the costs of any additional features then paid for either by charities such as the Muscular Dystrophy Campaign or the individual themselves. Bradford Wheelchair Services also picks up the often substantial bill for the ongoing maintenance of the chair, something which other Wheelchair Services will often not provide for modified chairs. It saves the family or charity as much money as possible by ordering the wheelchair from the supplier with the extra features included so that the family only need pay NHS rather than private prices. The manager of Bradford Wheelchair Services puts its success down to the belief that the way to get results is by working with other people, trying to be as flexible as possible when discussing what individuals want and need from their wheelchair and working with anyone that can help fund the wheelchairs that individuals need.

Sue has tried to emulate this joint-funding scheme in other areas but has consistently come across barriers to cooperation, with Wheelchair Services claiming that there is no funding, that the procedures do not exist for such a scheme or that it is against health and safety regulations.

## **Appendix 3: Birmingham Wheelchair Services – Delivering an Effective Service**

Following serious concerns in 2009 from commissioners in Birmingham about the unacceptable length of time from referral to supply of a wheelchair, Birmingham Wheelchair Services (which is commissioned by the three Birmingham PCTs to provide wheelchairs for adults and children in the city) was required to find ways to bring itself within the 18 weeks Referral to Treatment standards expected of other health services for both adults and children.

In response to these concerns, Birmingham Wheelchair Services underwent a formal LEAN process analysis in the latter half of 2009 to identify opportunities for streamlining the pathway and meeting the needs of service users in a more timely way. As a result of this exercise it completely re-designed its 'referral to supply' pathway and is in the process of implementation that should be concluded by December 2010. The time from receipt of a referral to assessment has been shortened to five working days (one week) for urgent cases and to 20 working days (four weeks) for non-urgent cases with similar reductions in the period of wait for supply of the wheelchair.

We welcome this swift action taken by Birmingham Wheelchair Services to address the long waits people living with neuromuscular conditions were experiencing for the right wheelchair, and the subsequent reductions in waiting times. We look forward to this new model being used for all wheelchair assessments, and further improvements to the service.

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