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The economic benefits of better provision of equipment for disabled and terminally ill children

Report for the British Healthcare Trades Association

May 2014

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Executive Summary

This is the summary of a report by Centre for Economics and Business Research (Cebr) on the potential benefits of an improvement in the availability of equipment for disabled and terminally ill children. The key findings of our analysis are:

- More than one in twenty children (5.7%) in the UK is disabled in some way.
- Specialist equipment, including wheelchairs, seats, communication aids, beds and postural support systems, plays a vital role in protecting the health of disabled children and those who care for them.
- At present, this equipment is under-provided by the bodies which have a statutory obligation to ensure that the needs of disabled children are met.
- This failure to provide equipment is worsening existing conditions and leading to complications which necessitate additional medical intervention.
- This costs dearly in terms of avoidable pain and suffering, as well as creating a substantial medical bill for surgery, hospital admissions, therapeutic interventions and physiotherapy.
- Our model suggests that the current cost of treatment for disabled children, made up of both medical costs and spending on equipment, was just under £1.9 billion in 2013.
- The vast majority of this spending (around £1.6 billion) was on medical care, while just £0.2 billion was spent on equipment. This figure is based on a calculation around the total size of need, and the proportion of need which is currently being met rather than a more robust estimate from public spending figures. This public expenditure data simply does not exist.
- It would cost £0.5 billion each year to provide every disabled child with all the equipment they need. This entails more than a doubling of present day spending.
- Even if the reduction in the need for surgical and other interventions driven by the improved availability of equipment is modest, these additional equipment costs could be recuperated. If, as case study evidence suggests, the relationship between equipment and demand for other medical treatments is stronger, investment in the provision of equipment could stimulate significant savings in healthcare costs.
- To recoup the cost of providing every disabled child with all the equipment they need, the proportion of children requiring surgery or treatment with Botox A, and related hospital admissions, appointments and physiotherapy must be reduced by a more than a third.
- If the proportion of disabled children requiring additional treatment was halved by proper provision of equipment this would be associated with a £ 0.13 billion per annum reduction in the total cost of caring for disabled children.
- If 80% of surgery and Botox A treatment taking place in the current world scenario was avoided though better provision of equipment, this could provide savings of £0.47 billion.

- These estimated savings are likely to be conservative given the evidence that the population of disabled children is likely to increase and that the proportion of disabled children with severe disabilities is also expected to increase in the future.
- The cost savings are likely to be much greater if further research is undertaken to consider the implications for the health of carers, the well-being benefits to both disabled children and their carers and the possibility that, by improving the health of some disabled children, some carers may be able to return to work.

1 Introduction and background

This is a report by Centre for Economics and Business Research (Cebr) on the potential benefits of an improvement in the availability of equipment for disabled and terminally ill children.

1.1 Equipment for disabled children

In 2013, there were approximately 725,000 disabled children aged 16 or under in the UK – 5.7% of the total population of this age group.[1] These children are affected by a wide range of conditions. Cerebral palsy is the most common cause of childhood disability, but others are affected by spina bifida, hydrocephalus, epilepsy, congenital deafness or other genetic disorders, or have acquired disabilities as a result of illness or suffered life-changing injuries in accidents. Their abilities and the extent to which they require care and assistance beyond the needs of other children depends on the conditions they are affected by and the severity of their individual case.

These needs, in turn, determine the needs for equipment among individuals. Children with many different disabilities require equipment of some sort to carry out day to day activities, remain mobile, communicate with the world around them and/or prevent their condition from deteriorating further. The types of equipment required vary according to the condition of the individual child. Equipment may be required for medical reasons – to protect body shape, help a child get the nutrition they need, or to protect carers who must physically lift children to wash, change and dress them.

Equipment also plays a social role, helping disabled children to get the most out of life. As such, equipment can form part of a disabled child's treatment plan as a form of occupational therapy, physiotherapy or specific medical treatment. From facilitating the absolute necessities of care – washing, toileting and ensuring safety – to devices that enable children to live life to the fullest extent possible – to remain mobile, or to communicate their needs and wishes effectively - specialist equipment is essential to maintaining quality of life among children with disabilities and those who care for them.

Children with neurological or motor impairment (caused by conditions such as cerebral palsy and muscular dystrophies) may have difficulties moving in a varied and symmetrical way, which prevents their body shape from developing in the correct way. This affects a child's ability to lie and sit comfortably, as well as their ability to stand and walk (if it is at all possible for them to do so). When posture and body position are not well managed, these difficulties can lead to body shape distortion, in ways that may be destructive to overall health. For example, a spine that develops a scoliosis can lead to internal organs becoming constricted or an impaired ability to swallow. This can also cause skin damage, reduce mobility and cause respiratory problems. These complications are often painful, reduce the

1 This figure is calculated using Office for National Statistics (ONS) mid-year population estimates for 2012 and an estimate of disability prevalence among under 16s drawn from the ONS' General Lifestyle Survey 2011. Disability is defined under the Equality Act 2010 as a description applying to any individual who has a physical or mental impairment which has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities.

ability of individuals to lead full and active lives and can increase the risk of premature death. [2]

Where these problems develop, the child is more likely to suffer from lower limb fractures and dislocations and is more likely to need orthopaedic surgery as well as additional pain management. Some children and young people may develop serious problems with their respiratory system and other major organs and can become seriously ill or even die. Carers also risk physical injury when handling and physically lifting disabled children to complete daily care tasks. Such complications and injuries impose a significant cost burden on the NHS. This is on top of the significant costs faced in terms of reduced quality of life for both the child, their carers and their families. These may include mental health costs due to a loss in the quality or quantity of sleep and reduced inclusion in education, which have, in turn, deleterious consequences for their quality of life.[3]

An adequate supply of specialist equipment can be a major factor in the effective management of patients' conditions and in the prevention of future problems like those outlined above.[4]

1.2 Policy context: the prevailing model for the provision of equipment

Where the necessary equipment is not provided, a child's development can suffer, as may their health and that of those who care for them. The failure to provide adequate equipment can prevent a child from meeting their full potential in terms of mobility and independence and can make it more difficult for them to make their needs known, causing enormous frustration and mental distress. The absence of adequate or any equipment can also compound existing medical conditions or create new problems, often through avoidable accidents. It also exerts a toll on those caring for disabled children, who may injure themselves, become mentally exhausted attempting to keep their child safe, or go into debt to purchase equipment themselves.[5]

At present, the legal obligation to provide equipment for disabled children is spilt between several local bodies. Responsibility for the provision of equipment for daily living and non-medical needs falls on local authorities, primarily under the 1989 Children's Act. This includes equipment to increase a child's independence, and their social care needs. As such, local authorities should help arrange for the provision of equipment which increases the safety, comfort and convenience of a disabled child, and equipment which makes meeting their care needs easier and safer.[6] Local Authorities are also required to budget for the provision of equipment for disabled children within schools to facilitate access to education. These funds are passed to schools in the education budgets set by each local authority, and decisions over what to buy with the money are made by school governors. Clinical Commissioning Groups (CCGs) are responsible for the provision of equipment which is specifically for medical or nursing purposes, like specialist beds, under the 1970 Chronically Sick and Disabled Persons Act in England and Wales, and equivalent legislation in Northern Ireland and Scotland. They are also responsible for the provision of wheelchairs and specialist buggies.

This fragmented system has led to confusion over which body is responsible for particular pieces of equipment. Evidence from the Newlife Foundation suggests that healthcare professionals have become jaded with systems for the provision of equipment through official routes due to a lack of funding and locally-imposed standards that prevent them from prescribing the equipment children really need. An increase in the number of applications

2 People with learning disabilities are a "high risk group for deaths from respiratory problems", particularly related to aspiration of food and drink which increases the likelihood of chest infections. Heslop et al (2013), "The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)", final report, Norah Fry Research Centre.
3 The North West Group of Paediatric Physiotherapists and Children's Occupational Therapists (2007), "Good Practice Guidelines to 24 hour Postural Management."
4 CIPOLD recognised the importance of "proactive postural care support", which would include provision of necessary equipment, in reducing the risk of aspiring. Heslop et al (2013), "The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)", final report, Norah Fry Research Centre.
5 Bennet (2010), "Counting the Costs 2010, Contact a Family", find that more than a quarter of parents had taken loans, with 11% taking loans to pay for equipment.
6 Contact a Family (2013), "Aids, equipment and adaptations: information for families".

for funding made to the charity in recent years suggests that the needs of disabled children are not being met by those who should be meeting them, and that children are suffering as a result.[7]

Despite the potential for significant health and quality of life benefits for patients, financial benefits to the NHS and economic benefits to the wider economy that could be derived from comprehensive provision of suitable equipment to disabled children, provision remains fragmented and non-systematic at best, and barely existent in some cases.

The lack of a sole body with the power and resources to provide equipment means many children fall through the gaps – leaving charities or families to pick up the cost. Where this is the case, children can be left without equipment that, at best, limits their quality of life or, in the worst cases, can cause serious injury or death.

The expected increase in the number of disabled children in the UK, due to increasing survival rates for premature births, the higher average age of parents and the improvements in treatment options for serious illnesses, will only exacerbate these problems.

Consequently, there are significant benefits to be harnessed by resolving the problems with the current system for the provision of children's equipment and moving towards a new, streamlined model. Ensuring that every child has the equipment they need would, firstly, reduce the costs of medical care required to deal with problems caused by a lack of necessary equipment, or equipment which is unsuitable or poorly fitted. This could reduce the bill for orthopaedic surgery and related costs, including hospital stays for children with complex needs, pain management and rehabilitation.

Secondly, adequate provision of equipment would make life simpler and safer for those caring for disabled children, reducing the healthcare bill for the injuries carers sustain and their poor mental health, bringing quality of life benefits. There are also potential productivity benefits if carers are able to seek employment due to a reduction in the amount of care they need to provide. Thirdly, the provision of suitable equipment would bring substantial benefits to disabled children themselves, in terms of improved quality of life, ensuring that they are able to fulfil their potential, raising self-esteem and preventing pain and trauma, both mental and physical.

This report endeavours to provide estimates of these benefits. However, any such estimates can only ever claim to be approximate or indicative due to the significant dearth of research in the area and of data to support such research. The estimates presented in this report can, likewise, only be said to be indicative. They are based on assumptions that cannot be confirmed and that will be realistic in some cases but not in others. We have, therefore, endeavoured to use conservative assumptions so that the estimates are likewise more conservative than we might have been able to put forward if there were adequate data.

The paucity of data has also limited the scope of this report. We provide a quantitative estimate of the cost savings that could be made if provision of equipment reduced the amount of medical treatment needed by disabled children. This is only one part of the savings we would expect to follow from better provision of equipment for disabled children: there are good reasons to believe that the health of carers would also improve, further reducing the costs to the NHS, and some carers may be able to return to work, providing productivity and tax benefits to the rest of the economy. There are also likely to be significant benefits in quality of life improvements, but estimating these, too, is beyond the scope of this report.

7 BDF Newlife (2012), "From the Front Line: Reporting on the UK's disabled children's equipment provision".

1.3 Structure of the report

The remainder of this report is structured as follows:

- Section 2 provides further background on the current state of play in the provision of equipment for disabled children and the areas that have been assessed as needing change. This provides the context for describing the methodology we endeavoured to adopt for the study, the difficulties encountered in implementing that methodology and the manner in which we had to adapt and narrow the focus of the methodology to suit the limited data that were available.
- Section 3 presents our estimates of the medical care cost savings that could be achieved by improving the availability of equipment to disabled children.
- Section 4 considers the additional benefits that could be achieved through improvements in the provision of equipment to disabled children, through improvements in quality of life and prognosis and social care costs.
- Section 5 summarises our findings and concludes.

2 Approach and methodology

This section outlines the challenges faced during our study, particularly in terms of the lack of existing relevant research or data and the implications of this for the methodology adopted.

2.1 The current state of play

Children are not being provided with the equipment they require…

While very little systematic research has been carried out on the equipment needs of disabled children, Beresford et al (2001) carried out a national survey of families with disabled children. These were found through the Family Fund Trust database. This was the first systematic survey of equipment use and needs among disabled children since 1985.[8] This research found that over a third of disabled children in the UK needed at least some help with sitting and almost half needed some help to stand. Two-thirds reported the need for some or lots of help to move about or to eat and drink. Developmental delay, associated with many conditions, also necessitates help with using the toilet and with getting dressed for eight out of ten disabled children, according to this survey.

There are difficulties with carer-reported equipment needs – particularly given that information about appropriate equipment is not always available to parents and carers. Likewise, they may not know what help their child would benefit from. Despite these limitations, almost all respondents to the survey said that they had an unmet need for equipment – just one in 20 families with disabled children said that they had access to all the equipment they needed. More than one in 10 respondents currently had no equipment at all.

The sample for this survey potentially underestimates equipment need, as take-up of the services provided by the Family Fund Trust is estimated to be between 50% and 70% of eligible families. Those who do not take up this support are more likely to have young children, whose needs due to disability are difficult to disentangle from age-related care needs. For other families, a lack of knowledge about available support could also explain the lack of engagement. Those who have not been informed of the support available

8 Beresford et al (2001), "Community Equipment: Use and needs of disabled children and their families", Social Policy Research Unit, University of York, research for Department of Health.

through charities like the Family Fund Trust will also presumably not have benefited from the support they provide in terms of provision of equipment, and so may be more likely to lack equipment than households with disabled children who make use of this provision. This survey is thus likely to underestimate the problem of equipment shortages across households with disabled children in the UK.

At present, provision of equipment is patchy at best…

Under the present system, responsibility for providing equipment is split between several different bodies. Statutory bodies (local councils) are liable for the costs of pieces of equipment required for daily living and access to education under the 1989 Children's Act, in line with their responsibilities for care and education. Other pieces of equipment fall under health budgets, under the 1970 Chronically Sick and Disabled Persons Act and are correspondingly within the remit of CCGs.

However, evidence suggests that, at present, these bodies are failing to provide adequate levels of equipment for disabled children. Newlife reported in 2012 that more than three-quarters of the front-line professionals – nurses, occupational therapists and physiotherapists – who contacted them felt there was no point in applying to local statutory services for funding for equipment before applying to charities like Newlife.

Likewise, in over 90% of applications to the charity, professionals cited locally set restrictions on access to equipment or a lack of funds, which meant that equipment cannot be provided by the local services who are officially responsible for them.[9] The Care Quality Commission (CQC) report provides further evidence that locally set limits on care are a significant problem: the CQC 2012 review found that a third of PCTs have criteria for specialist seating and wheelchairs (for example, a minimum age for the provision of wheelchairs, or a limitation that only one seating system can be provided, although most children requiring such provision will need one chair at home and one at school), though no questions were asked about the provision of other equipment, such as car seats, sleep systems and walkers. The number of applications for charity support for the provision of equipment suggests that there is a significant unmet need for equipment across the UK.

Beresford et al (2001) also present evidence of under-provision by the state. Over a quarter of families were found to have self-funded equipment[10] – a proportion that is likely to have increased over the years since the financial crisis with Newlife reporting that budgets for equipment for children have been squeezed ever more tightly and that the number of requests received has risen significantly.

The system also makes it impossible to know the true scale of need…

Apart from this failure to provide appropriately for disabled children and young people, the system is also preventing accurate measurement of the scale of the problem. Where professionals have decided that it is no longer worth the time needed to apply to statutory services for equipment for disabled children, local services have less and less of an idea of the scale of need that is not being met.

This weakness was brought sharply into relief by the Care Quality Commission's (CQC) 2012 report. When Primary Care Trusts (PCTs), the predecessors of CCGs, responsible for commissioning secondary care) were asked how many disabled children and young people were in their area, most had to estimate. Nearly half (44%) of all PCTs said they did not know how many referrals had been made for equipment for children and young

9 BDF Newlife (2012), "From the Front Line: Reporting on the UK's disabled children's equipment provision".
10 Beresford et al (2001), "Community Equipment: Use and needs of disabled children and their families", Social Policy Research Unit, University of York, research for Department of Health.

people for manual and powered wheelchairs, and another 16% said they had no referrals made. Many parents who participated in focus groups as an input to the CQC report talked about experiences being stressful and frustrating.[11]

Analysis of requests for funding received by Newlife also paint a picture of a failure to provide by statutory services. In nearly half of all referrals to the charity, healthcare professionals blamed restrictive equipment lists (46%), while 12% felt locally set criteria (for example, a decision to not allow any children under the age of 11 to have motorised wheelchairs, despite the professional's view that this is the equipment best suited to the child's needs) prevented equipment from being accessed. One in ten also cited rationing as a problem while one in five referrals was blamed on lack of local funds. Together, this evidence suggests than nine out of ten refusals to fund equipment are a result of inadequate budgets and a poor understanding of need – with these refusals conflicting with the considered view of professionals.

The CQC have been absolutely clear in their assessment that the current system is not fit for purpose:

> *"Without a basic awareness of what the needs of the local population are, it is hard to understand how [local care commissioners] can assure itself it is commissioning services to meet them. We therefore urge commissioners to improve the quality of information they hold about these services."*[12]

Changing the system could bring significant benefits, not just in cost savings associated with a reduced need for surgical intervention and medical care, but also in improved quality of life for both disabled children and their families.

2.2 What needs to change?

At present, the evidence suggests that statutory authorities are failing to meet their obligations to provide disabled children with all the equipment they need to live comfortably and safely. A lack of understanding of the scale of need for children's equipment and scarcity of resources committed to its provision are causing suffering and costing the economy dearly in unnecessary healthcare costs, lost productivity and reduced quality of life for disabled children and carers alike.

If the evidence is representative, something needs to change. The system needs to ensure that all disabled children are assessed for all their equipment needs, and receive equipment that is well suited to their individual circumstances and that maximises their access to day-to-day activities, reduces the amount of care required and protects the health of both disabled children and their carers. And all of this needs to be provided in a timely manner.

The ideal system would ensure that all children who need postural management have access to suitable equipment, including seating, walkers, wheelchairs and sleep systems as necessary. At present, orthopaedic operations are the single biggest cost relating to under-19s with spastic cerebral palsy, according to the National Institute for Health and Clinical Excellence (NICE).[13] In many cases this is due to a failure to provide the equipment that would allow children to maintain mobility and strength in joints. This failure has caused problems like hip dislocations, distortions of the lower limbs and scoliosis, all of which can necessitate costly surgery, pain management, hospital stays and rehabilitation.

11 Care Quality Commission (2012), "Health care for disabled children and young people: a review of how the health needs of disabled children and young people are met by the commissioners and providers of healthcare in England".
12 Care Quality Commission (2012), "Health care for disabled children and young people: a review of how the health needs of disabled children and young people are met by the commissioners and providers of healthcare in England".
13 National Institute for Health and Clinical Excellence (2012), "Spasticity in children and young people with non-progressive brain disorders", Costing report: Implementing NICE guidance, NICE clinical guideline 145.

NICE have accepted that the cost impact of implementing guidance on the management of spasticity – one of the main causes of body shape distortion and the resultant problems – would not be significant, but that savings could be realised later in life if effective early management reduced the need for further treatment. Although NICE have not yet evaluated the potential benefits of the use of equipment to manage the health of disabled children, case studies suggest that the benefits could be significant.

Our review of literature like the Newlife report suggests that amongst the priorities should be:

- Provision of suitable wheelchairs to ensure that children are as mobile and independent as possible, which is critical to their well-being and broader health.
- Provision of specialist beds, car seats, hoists and other handling equipment, which are essential to prevent injury to both disabled children and their carers during routine care tasks like washing and dressing.
- Provision of equipment to allow carers to look after disabled children at home as far as possible, which obviates the need for children to be separated from their families and reduces hospital admissions.
- Provision of specialist beds that allow easy changes of position to relieve pressure, which can reduce pressure sores and the costs associated with caring for these.

Our discussions with BHTA members revealed the potential requirement for CCGs to build in provisions for the longer term, and most likely increasing requirement for equipment for premature babies & those with genetic disorders.

However, it has also been suggested that the provision of equipment alone will not put an end to the current problems. Equipment needs to be matched with training for carers and professionals, partnership working between professionals and families, broader support for families and provision for the replacement of equipment as children grow and develop.

In Wakefield, West Yorkshire, for example, a streamlined system of equipment provision and postural care has been put in place with what would appear to be remarkable success. Wheelchairs are moulded to children with asymmetry from less than a year old if needed, with a variety of other symmetrically supporting seating also provided. The clinic's caseload is prioritised so that no child waits longer than a month to be seen in a specialist clinic. The provision of equipment is combined with training for professionals and families and the development of partnerships between agencies and coordinated efforts to protect posture.

This approach has reduced body shape distortion among children and young people meaning fewer children suffer from hip dislocations and the need for preventative or reconstructive surgeries has fallen dramatically, with a commensurate reduction in demand for consultant appointments and pain management. The provision of suitable equipment alongside the necessary training and support for carers has played a key role in this achievement.[14]

2.3 The benefits we sought to measure and the problems encountered

Estimating the number of disabled children in the UK

Part of the difficulty around the provision of adequate equipment to disabled children in the UK is that there is no single, unified source of data on the

14 Suzanne Carter, "Why does postural care work in Wakefield?"

prevalence of disability. While various official national surveys tap into elements of childhood disability there is no single database which records the prevalence of disability. The most widely accepted figure, used in this study, is drawn from the ONS' General Lifestyle Survey. This annual survey records the number of children affected by "limiting long-standing illness or disability", reported to be 725,000 0-16 year olds in 2011 (the most recent year for which data is available). This suggests a prevalence rate of 5.7% meaning that more than one in every 20 children is disabled in some way.

Other measures report different levels of disability prevalence, however. The annual Schools Census provides a timely estimate of the number of children with Statements of Special Educational Needs (SEN), while the number of children registered as receiving Disability Living Allowance (DLA) is also used as a measure of disability prevalence. However, each of these may underestimate the prevalence of disability because some disabled children may not have SENs, and this measure also has limited value in counting pre-school children. Meanwhile, not all families with disabled children will be eligible for or claim DLA.[15]

The Thomas Coram Research Unit suggests that the best estimate of disabled children would use the number of children with an SEN statement or receiving DLA (whichever is greater) as a lower bound and the sum as an upper bound.[16] We dismiss this method, as the lower bound is likely to be an underestimation and the upper bound would involve double-counting. Nonetheless, the upper bound produced using this method is broadly in line with the estimate of prevalence based on the General Household Survey and we believe the methodology used in the latter calculation is more robust.

Understanding the nature of disability and the needs of the UK's disabled children

The prevalence of different types of disability among children and young people across the UK is even less well recorded. While it is possible to access some data on levels of severity among cerebral palsy sufferers, it is essentially impossible to estimate how severely children with other conditions are affected by their disability – the proportion who are able to walk unaided, the proportion who have communication difficulties and other factors that influence the demand for equipment are largely unknown.

While the number of requests for equipment made to charities provides some insight into the scale of the equipment shortage faced by the UK's disabled children, there is also a lack of information at the national level about equipment needs.

Assessing the link between the provision of equipment and improved clinical outcomes

There is also very little systematic data available on the ways in which equipment can reduce the healthcare costs associated with certain types of disability, or on the outcomes and costs associated with failure to provide suitable equipment. Although equipment is increasingly recognised as an important part of the management of many long-term disabilities, we have been unable to find any studies evaluating treatment pathways focused on its use. Case studies – like the case of postural care in Wakefield – suggest that improvements in equipment provision can engender improvements in outcomes, but such methods have not yet been formally tested through randomised controlled trials or similar medical studies.

15 Read, (2007), "Can we count them? Disabled children and their households: Full Research Report", ESRC End of Award Report, RES-000-22-1725. Swindon: ESRC
16 Mooney, Owen and Statham (2008), "Disabled Children: Numbers, characteristics and local service provision", Thomas Coram Research Unit, Department for Schools, Children and Families.

2.4 Methodology

These difficulties have constrained the comprehensiveness and robustness of the methodology that it has been possible to use for our study. We initially aimed to quantify all the benefits that would be associated with the better and more comprehensive provision of equipment to every disabled child that needs it. But a number of data difficulties (outlined above) have limited our ability to undertake this analysis, and the findings presented in section 3 below are thus based, to an extent, upon extrapolation and assumption.

To model the cost of care for disabled children under the current system, in which under-provision of equipment is leading to additional costs in surgery and related care, relative to costs in a world where all children have access to all the equipment they need, we needed data inputs including:

1. An estimate of the number of disabled children in the UK and the severity of their disabilities.
2. An understanding of what sort of equipment children with different disabilities and different severities need and the costs associated with this.
3. An understanding of current treatment pathways for disabled children and the costs of these pathways, e.g., what proportion of children need surgery and other treatments and what are the costs associated with this?
4. A view of how treatment pathways would be likely to change if equipment provision was such as to meet the entirety of the unmet need, e.g., how much would the need for surgical procedures and other treatments fall and what would be the cost implications of this?
5. Evidence of how the provision of equipment can reduce the incidence of injury and illness among carers of disabled children.
6. Systematic evidence on the well-being benefits disabled children and carers experience when provided with all necessary equipment

We were able to find enough data to consider the first four parts of this study. However we have been unable to find sufficient data to study how equipment for disabled children can reduce injuries among carers or how equipment improves well-being. This study thus focuses exclusively on the likely cost savings associated with reduced healthcare costs for disabled children if provision of equipment is improved. We acknowledge that there are likely to be further benefits in terms of reduced healthcare costs for carers, the potential for carers to re-enter the workforce in some cases and significant improvements in well-being for both children and carers. However, estimating the scale of these savings is beyond the scope of this report given the paucity of data on the effectiveness of treatment with equipment at present.

It has also been necessary to focus our research more closely on the costs and benefits of providing disabled children with appropriate postural support. As treatment pathways for disabled children who require equipment for other reasons are not well established, estimating treatment costs, the potential medical benefits and cost savings associated with provision of equipment proved impossible. This means that our estimated medical savings are likely to be relatively conservative, as in reality additional savings could be realised as provision of equipment successfully prevents other medical conditions and associated costs being incurred.

Estimating the number of disabled children in the UK and their level of disability

The starting point for our model was an estimate of the number of disabled children in the UK population at present and how this is likely to change in the future. We used the prevalence figure of 5.7% suggested by the ONS' General Household Survey 2011, and estimated the total number of disabled children this would imply across the UK now and in the coming years using ONS population projections.

However, there are reasons to believe that the prevalence of disabilities among children will actually rise in the coming years, as the average age of parents rises and as survival rates of premature babies and those with complex childhood illnesses increase. However, in the absence of a basis to estimate what future prevalence levels might be, we have adopted the conservative assumption that prevalence will remain constant over time.

Given the absence of readily-available data on the severity of childhood disabilities across the UK population, we used information relating to children with cerebral palsy, the most common cause of childhood disability in the UK and probably the only condition for which there are useful data. The extent to which cerebral palsy limits a child's independence and day-to-day activities can be measured using the Gross Motor Function Classification System (GMFCS). This scoring system considers the extent to which children are able to sit, stand, balance and move independently, the extent of visual and hearing impairments and learning difficulties. On this basis, the system places children into one of five numbered categories, where one is the least severe and five is the most severe. Further details on the abilities and difficulties of children in each group are presented in Table 1 below.

Table 1: Gross Motor Function Score characteristics

GMFCS score group	Characteristics
1	Can stand and sit independently
	Can achieve midline with hands, feet and legs (bring limbs to the centre of the body)
	Full range of pelvic movements
	Can move from one position to another (i.e. sitting to prone and back again)
	*Mild or no learning disabilities**
2-3	Can be placed in sitting or standing
	Some ability to move limbs independently
	Controlled eye movements
	Can recover balance when moved to either side
	Hands can be brought to the midline
	*Mild learning disabilities**
4-5	Unable to sit or stand independently
	Asymmetric posture and movement
	Uncontrolled arm movements
	Strong tendency to extend, high muscle tone or extreme floppiness
	Complicated body shape distortions
	Visual impairments
	Hearing impairments
	Dysphagia (swallowing difficulties)
	*Complex learning disabilities**

Source: Information provided by British Healthcare Trades Association Children's Equipment Group members
** Learning disabilities are not usually included in GMFCS classifications, which focus on physical disability. Our discussions with British Healthcare Trades Association members suggest that the probability that a child is affected by learning disabilities increases with the severity of physical disabilities.*

These scores are not approved for application to children with conditions other than cerebral palsy or, in some cases, Down's syndrome. However, in the absence of other data on the severity of childhood disabilities, we have used these to estimate the severity of disability across the population. We have also, using the guidance of British Healthcare Trades Association members, considered how the probability and severity of learning disabilities varies with the severity of physical disabilities. For those with learning disabilities, communication aids are as vital to well-being as the equipment required to alleviate physical disabilities, as recognised in Scope's No Voice, No Choice (2009) review and the "Bercow Review".[17,18]

Given this, we were keen to include communication aids in our analysis, and use the assumptions set out below to model the demand for and provision of this type of equipment.

Cerebral Palsy Register data, collected across the UK between 1981 and 1997, provides an indication of the relative prevalence of each of these GMFCS levels of disability. These data suggest that more than two-thirds of children with cerebral palsy (69%) fall into GMFCS groups 1-3 – that is, they have moderate disabilities and are able, with the right support, to lead relatively independent lives. Analysis of international data on those with a diagnosis of cerebral palsy suggests that around half of this group (48%) are in the lowest GMFCS band, while the remaining 52% have slightly more severe disabilities.[19] The remaining 31% have more severe disabilities, placing them in the GMFCS 4-5 category. These children require much greater assistance with every day activities such as eating, washing and dressing.

Given the absence of information on the severity of disability among children with other conditions, these proportions were applied to the UK population of disabled children as a whole to give estimates of the number of severely disabled and moderately disabled children which were then used as inputs to our cost modelling. These proportions suggest that in 2013 there were 500,000 children with moderate disabilities and 225,000 children with more severe disabilities in the UK.

Equipment needs, associated costs and current provision

The type and severity of a child's disability will determine, to a large extent, their equipment needs. Children who are unable to maintain a symmetric position independently, for example, are more likely to need equipment to support their posture, including seating and sleep systems. The needs of children with less severe disabilities are likely to be less complex; they may be able to use manual rather than powered wheelchairs, for example, and require fewer adaptations.[20]

Obviously the equipment required will vary substantially depending on the individual situation of each child and their needs. However, given the general characteristics of children in each of the GMFCS groups, a list of equipment which is likely to be required can be developed. Table 2 below gives the equipment likely to be required by a child given their GMFCS group. Some disabled children need more equipment than this baseline, while others need less. Therefore, on balance, this list is likely to be a reasonably fair reflection of the needs of the population of disabled children as a whole.

The list provided in Table 2 is used in our model to estimate both current levels of spending on equipment and the amount of spending that would be needed to ensure that every disabled child has all the equipment they need. The total amounts estimated are broadly in line with Newlife's estimate that it costs around £20,000 to provide for a child with complex needs.[21] Our

17 Scope (2009), "No Voice, No Choice: A sustainable future for Alternative and Augmentative Communication".
18 DCSF / DH (2008), "Final Report of the Bercow Review of Children, Young People and Speech, Language and Communication".
*19 Reid, Carlin and Reddihough (2011), "Using the Gross Motor Function Classification System to describe patterns of motor severity in cerebral palsy", Developmental Medicine and Child Neurology, **53**, pp. 1007-1012. These data are used in preference to the findings of the UK Cerebral Palsy register which suggest that only 14% of children fall into the lowest GMFCS classification group, at odds with other international studies including Read, Carlin and Reddihough and Avery et al (2003), "Rasch analysis of the gross motor function measure: validating the assumptions of the Rasch model to create an interval-level measure", Archives of Physical Medicine and Rehabilitation, **84**, pp697-705.*
20 For children with the most severe disabilities, equipment may need further adaptations; for example, for those who cannot operate traditional controls, different switches may be needed, or for those with severe postural problems additional moulding or supports may be required to make equipment suitable.
21 BDF Newlife (2007), "It's not too much to ask", BDF Newlife

Table 2: Equipment needed by GMFCS group, and indicative prices (per piece of equipment)

GMFCS levels	Equipment needed	Indicative price
1	Self-propelled wheelchair	£702
	Walker	£169
	Shower chair	£342
	Indicative total	£1,213
2-3	Manual wheelchair	£1,723
	Electric wheelchair	£3,178
	Alternative seating	£1,858
	Communication aid	£4,248
	Sleep system	£431
	Standing frame	£1,272
	Walker	£960
	Shower chair	£342
	Indicative total	£14,010
4-5	Manual wheelchair	£1,723
	Electric wheelchair	£3,178
	Alternative seating	£1,858
	Communication aid	£4,248
	Assistive bed	£3,350
	Sleep system	£1,032
	Tracking hoist and sling	£2,250
	Standing frame	£2,480
	Shower chair/table	£1,513
	Indicative total	£21,631

Source: Information provided by British Healthcare Trades Association Children's Equipment Group members, some indicative prices taken from the Disabled Living Foundation's Living Made Easy website: http://www.livingmadeeasy.org.uk/children/

model estimates the annual aggregate cost of equipment across the UK on the basis that this spending is spread equally across 16 years of childhood. While in reality the volume of spending over an individual's childhood is likely to vary significantly between children, with potentially higher costs for younger children, the relatively even dispersal of children across the childhood age groups in the child population as a whole means that this assumption is not unrealistic at the aggregate level.[22]

As the evidence summarised above makes clear, disabled children across the UK do not, at present, have access to all the equipment they need. Establishing how much of this equipment children currently have, however, is much more difficult, as no recent research has systematically reviewed the extent to which children's needs are met at the national level. The latest research we have been able to find that considers the level of under-provision of equipment is Beresford (2001). This research suggests that as much as 60% of all equipment needs are unmet.[23] While the survey data on which the study was based is now relatively old, it does at least provide a reasonably conservative basis upon which to build our model. If anything, it is likely that the extent of unmet need now is greater in light of the squeeze on

22 Furthermore, there was insufficient information to take account of issues like children needing multiple iterations of particular pieces of equipment. But, while some children will need more equipment (and for some to be replaced as they grow), others will not need everything on the list. The question then is whether these opposing drivers of the total need for equipment balance each other out. If they do, our estimates should be broadly representative of reality.

23 This proportion was calculated from the results published by Beresford by taking the proportion of respondents reporting a met and unmet need for a certain type of equipment. This information combined with the estimate of the UK's population of disabled children in 2013 from the ONS General Household Survey and ONS population estimates to estimate the scale of total need and unmet need

public resources since the 2008 financial crisis. This means that the following analysis may underestimate the extent to which equipment is under-provided at present and, consequently, may also underestimate the savings that could be made if provision of equipment was increased to ideal levels.

This information on the cost of equipment needed and the extent to which that need is met is combined with the data on the population of disabled children discussed above to provide estimates of:

- the total amount spent on equipment each year at present; and
- the amount that would need to be spent in an ideal world to ensure the equipment needs of all disabled children are fully met.

Current treatment pathways

Treatment for children with physical disabilities often involves a combination of physiotherapy, occupational therapy, postural management, orthotics and therapeutic medication such as the administration of Botulinum (Botox) A. Orthopaedic surgery may also be used in cases where the individual suffers from significant problems with body shape, joints or limb formation. The combination of treatments and therapies prescribed will depend on the exact condition and circumstances of individual children.

Relatively little is known about what is considered a "standard" amount of intervention for a child with a particular level of disability. A survey of physiotherapists carried out by Coombe, Moore and Bower (2012), however, provides some insight into the average amount of intervention received each year by children with cerebral palsy. They found that children with GMFCS scores between 1 and 3 received, on average, 8.9 hours of physiotherapy a year, while children with GMFCS scores of 4 or 5 received 15.7 hours. More than one in ten children required treatment with Botox A (16.6%) and nearly one in ten required at least one episode of orthopaedic surgery (9.4%). For children who have either of these treatments, approximately 50% more physiotherapy is required.

The risk of conditions that necessitate surgery increases with the severity of the underlying disability, in most cases. Nearly half (43.3%) of all children with cerebral palsy and a GMFCS score of 4–5 have scoliosis (curvature of the spine), compared to 22.9% of those with a GMFCS score of 1–3. Among the population of children who do suffer from scoliosis, this is more likely to be severe in those children with more limiting disabilities: just 3.6% of children with GMFCS 1–3 have moderate or severe scoliosis, compared to nearly a third of those with more severe disabilities (30.4% of those with GMFCS 4–5).[24] Protecting body shape is thus more important for those who have more severe physical disabilities. This information is used to model the likelihood of a child with a given level of disability having severe body shape distortions or other musculoskeletal problems which necessitate surgery or hospital admissions.

Information on the cost of orthopaedic surgery, physiotherapy sessions, Botox A treatment and time in hospital is available in the National Institute for Health and Clinical Excellence's (NICE) 2012 costing report "Spasticity in children and young people with non-progressive brain disorders".[25] These costs are weighted by the likelihood of needing treatment for GMFCS groups 1–3 and 4–5 separately, using the information detailed above, to provide an estimate of the average current cost of treatment per disabled child, per year. We are unable to consider the costs of treatment for other conditions or resulting from accidents potentially caused by a lack of equipment due to a lack of relevant data.

24 Persson-Bunke, Hagglund, Lauge-Pedersen, Wagner and Westbom, (2012), "Scoliosis in a total population of children with cerebral palsy", Spine 37(12)
25 National Institute for Health and Clinical Excellence (2012), "Spasticity in children and young people with non-progressive brain disorders, Costing report: Implementing NICE guidance", NICE clinical guideline 145.

The potential benefits of expanding the provision of equipment

Equipment, particularly items used to manage posture, plays an integral role in the care of disabled children. There is relatively little information available, however, on how the use of equipment changes a child's prognosis and affects the rest of the treatment pathway. Case studies, like those in box 1 below, suggest that the use of equipment to manage posture and protect body shape can reduce the need for other types of treatment. But, despite an exhaustive search, we have been unable to find any systematic research into the outcomes of treatment with equipment, in terms of improved postural outlook or changes in the likelihood of other medical complications.

What is clear, however, is that postural management is absolutely crucial to the management of complex disabilities. The "Confidential Inquiry into Premature Deaths of People with Learning Disabilities" (CIPLOD) found that over a third of people with learning disabilities died from respiratory disease, and that gastro-oesophageal reflux and constipation were common – all conditions exacerbated by poor posture and subsequent body shape distortions, which could be managed with equipment.[26] Further case studies from Newlife and other charities also show that failure to provide suitable equipment also commonly leads to accidents which impose further medical care costs.[27]

This evidence, along with the many other case studies provided by Postural Care, Newlife Foundation and others, suggests that the provision of equipment which protects body shape can reduce the need to carry out orthopaedic surgery, with all the associated costs – both monetary and human. The exact extent to which this is the case, however, is not clear. No data is available on, for example, the reduction in the number of spinal procedures which can be expected if all children who need them are given sleep systems, or the reduction in behavioural and psychological intervention needed if all children were provided with appropriate communication aids.

This lack of data means that our model has had to rely on assumptions. Given the complete paucity of data, we have considered a variety of possible relationships between the provision of equipment and the need for orthopaedic surgery and Botox A treatment, and report a full set of results in the next section.

Box 1: Case studies of postural management using equipment

Connor's Story – Postural Care (2011), Connor's Story

Connor has a diagnosis of cerebral palsy. His body shape became distorted through sleeping in a twisted position, leaving his pelvis rotated to one side and his body asymmetric. Plans were made to perform a de-rotation osteotomy to turn his left leg out. Before surgery, however, Connor was given a sleep system which allowed him to lie straight on his back with support. Over the course of three months, this corrected Connor's posture to the extent that surgery was no longer considered necessary.

Michael's story – BDF Newlife (2007), It's not too much to ask

Michael has cerebral palsy affecting all four limbs. He had surgery on both hips in 2004, and had problems after this with one hip in particular. Lack of suitable seating meant he sat on a beanbag and developed curvature of the spine. He subsequently needed corrective back surgery.

Craig's story – Postural Care (2010), It's my Life!

Craig had complex and severe disabilities. Although his posture was protected with seating equipment during the day, he was not correctly positioned while asleep and over time this led to a deterioration in his body shape. Craig developed severe scoliosis and, although he was assessed for surgery to correct this, his body shape had become so severely distorted by that point that surgery could not go ahead. His poor body shape seriously impaired Craig's respiratory function, which eventually made him seriously ill. Craig's distorted body shape was a significant factor in his premature death.

26 Heslop et al (2013), "The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)", final report, Norah Fry Research Centre
27 See BDF Newlife (2007), "It's not too much to ask", BDF Newlife for numerous examples

3 Medical care cost savings

This section presents the results of our analysis.

3.1 Current NHS expenditure on treatment for disabled children

Our model suggests that the current cost of treatment for disabled children, made up of both medical costs and spending on equipment, was just under £1.9 billion in 2013.

The average cost of medical care for a disabled child with a GMFCS score of 1-3 is approximate £1,600 each year, including the cost of orthopaedic surgery and associated consultant time, physiotherapy, Botox A treatment and hospital inpatient episodes. We were unable to consider the costs of pain relief due to a lack of data, meaning this cost is likely to be an underestimate in practice. The equivalent annual cost of treatment for a disabled child with a GMFCS of 4-5 in the current world is £3,700. Over the population of disabled children in the UK, this adds to £1.6 billion of spending on medical care each year.

We estimate, given the number of disabled children and the proportions in various GMFCS categories, that given Beresford's finding that 60% of equipment needs are unmet, approximately £0.2 billion was spent in 2013 on children's equipment. This figure is based on a calculation around the total size of need, and the proportion of need which is currently being met rather than a more robust estimate from public spending figures. This public expenditure data simply does not exist.

3.2 NHS expenditure under a new system for the provision of equipment

The proportion of this spending that could be avoided if every disabled child was provided with all the equipment they needed depends in practice on how much of the surgical and medical interventions being made today are driven by a lack of equipment and that could be avoided with better equipment provision. Case studies, such as those presented above, suggest that there is a negative correlation between the provision of equipment and spending on surgical and medical care. In other words, the better the provision of equipment is, the lower the need for corrective orthopaedic surgery and other procedures. The size of this negative correlation, however, is currently unknown.

We have, in the absence of such data, modelled the potential savings under a range of scenarios based on different sets of assumptions, with the results presented below.

Based on the indicative equipment lists and costings set out above, we estimate that it would cost £0.5 billion each year to provide every disabled child with all the equipment they need. This entails more than a doubling of present day spending (£0.2 billion).

But our analysis suggests that, even if the reduction in the need for surgical and other interventions (driven by the improved availability of equipment) is modest - that is, the negative correlation between equipment and the need for treatment is relatively weak – the additional equipment costs could be recuperated. Were the relationship between equipment and demand for other medical treatments stronger, as the case study evidence suggests, investment in the provision of equipment could stimulate further significant

savings in healthcare costs. Figure 1, below, sets out the potential scope of these savings.

The initial outlay associated with providing every child with all the equipment they need - essentially a doubling of spending on equipment - means that it is not automatically worthwhile in terms of healthcare savings (although the benefits in terms of quality of life and productivity may change this). Figure 1 suggests that to recoup the cost of providing every disabled child with all the equipment they need, a full 30% reduction in the need for surgical and other interventions in a given year might be required.

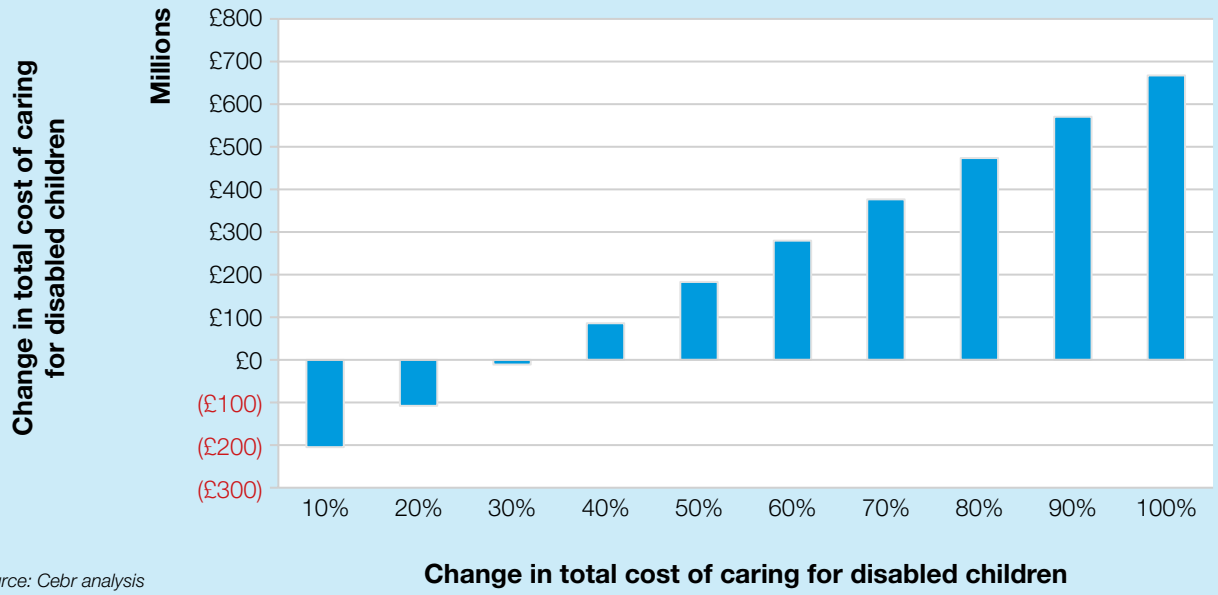
Case study evidence, however, suggests that the lack of suitable equipment and the subsequent deterioration in posture is a major cause of surgery and other costly treatments among disabled children. The reduction in the need for surgery could thus be much greater than this. If the proportion of disabled children requiring additional treatment in a given year was halved by proper provision of equipment, for instance, this would be associated with a £ 0.18 billion per annum reduction in the total cost of caring for disabled children - the cost of providing the additional equipment would, in other words, be more than offset by the reduction in medical care costs.[28]

To take another example, if 80% of surgery and Botox A treatment taking place in the current world scenario each year was avoided though better provision of equipment, this could provide savings of £0.47 billion, increasing to £0.57 billion with a 90% decrease in the use of other treatments. Investment in equipment for disabled children could thus not only pay for itself in terms of a reduced bill for healthcare - it could also provide substantial additional savings. Given the case study evidence, it seems more likely the savings would be in these higher ends of the range of estimates.

However, we also have reason to believe that the estimated savings are conservative given the evidence that the population of disabled children in likely to increase more than proportionately relative to the population as a whole and that the proportion of disabled children with severe disabilities is also likely to increase in the future.

28 We understand that the reality is more complex than simply equipment obviating the need for surgery. For some, the proper provision of equipment may only serve to postpone such intervention. But the postponement of surgery and the delayed need to incur such high costs is also valuable in economic terms when future costs are valued in present value terms, as is standard in appraisal in Central Government. Furthermore, in any given year, the postponed surgery simply reduces the likelihood or proportion of children requiring surgery in that year

Figure 1: Annual savings in cost of healthcare (vertical axis) for disabled children for given percentage reductions (horizontal axis) in the need for surgery etc. in a given year as a result of meeting the total need for children's equipment, £ millions, 2013 prices



Source: Cebr analysis

In reality, the relationship between the provision of equipment and the demand for treatments such as orthopaedic surgery is unlikely to be constant over time. Instead, it is likely that the reduction in medical treatment costs would be smaller in the early years of an equipment provision programme, and would rise over time. This is because the provision of equipment is, in many ways, a preventative strategy. Over time a programme that makes full use of equipment to protect body shape would be expected to have dramatic results on the number of disabled children needing surgery. However, in the short run, there will be a number of children for whom, sadly, the intervention will come too late. The damage already done to their musculoskeletal systems will mean that a higher rate of surgery is inevitable in the first few years of an equipment provision programme, meaning costs could remain higher for several years before falling. Without a better understand of how equipment can reduce the need for surgery, however, we are unable to model the precise profile of cost savings over time. Additionally, equipment costs could be lower than the estimates above if systems were put in place to maintain the condition of equipment as far as possible and recycle it.

This report provides only a first estimate of the savings which are likely to be made through better provision of equipment to disabled children. The cost savings are likely to be much greater when the implications for the health of carers is taken into account. Increased provision of equipment could provide additional savings through reducing the number of carers injured when handling and lifting disabled children without adequate support. The mental health of carers would also be likely to improve if, for example, the need to wake and care for children in the night or the amount of time spent worrying about safety was reduced. The improvement in quality of life for both disabled children and their carers is likely to be substantial. Additionally, by increasing the independence of some disabled children and improving their long-term prognosis, provision of equipment may allow some carers to return to work, bringing benefits in terms of increased economic activity, a reduced benefits bill and higher tax receipts. More research is needed to understand how the provision of equipment for disabled children influences the health of carers and the likelihood that they will work.

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