



Failing Disabled Children across the UK

Making the right decisions

September 2016

BHTA

British
Healthcare
Trades
Association

“A nation’s greatness
is measured by
how it treats its
weakest members”

Mahatma Gandhi



Foreword By Lord Rennard

This paper demonstrates how providing the right specialist equipment to disabled children can help to give them relief from pain, support their ability to receive appropriate therapy or treatment, and for many, improve their chances of leading fulfilling lives.

Investment in research and development has enabled British manufacturers and suppliers to provide some of the best equipment in the world. They work with professionals, charitable and voluntary organisations to reduce the frustration felt when children cannot get the equipment that they desperately need.

The lives of many more children can be saved than in previous decades, but they often need specialist equipment to improve their quality of life, attain greater independence and assist their families and carers.

Organisations supporting this paper, such as the Newlife Foundation for Disabled Children, believe that giving disabled children ‘the right equipment at the right time is essential and that failure to do so should be considered to be unacceptable’. It is about doing what’s right to enable disabled children to share the world.



Lord Rennard MBE

Director of Communications BHTA



The Context

Supporting the health and wellbeing of disabled children has to be a priority of the health service, social services and local authorities. From a humanitarian point of view we cannot fail to provide equipment, or allow children to use equipment which is not suitable and causes them secondary complications.

From a financial point of view it is not cost effective to allow children to undergo these secondary complications when the figures demonstrate that we could prevent these complications and negate the costs of intervening with them. As these children develop into adulthood there is evidence that they are a particularly vulnerable section of the population put at risk of premature death.

The Confidential Inquiry into Premature Death for People with Learning Disabilities found that on average, people with learning disabilities die 16 years earlier than the general population. CIPOLD* recognised the importance of 'proactive care support', which would include provision of necessary equipment, in reducing the risk of aspirating.

The Mazars Report** stemmed from CIPOLD and once again found that people with learning disabilities were at particular risk from choking and aspiration and needed more support to eat and drink safely. Once again, this would require the use of effective and timely equipment.

*Source: <http://www.bristol.ac.uk/cipold/>

**Source: <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

The UK is engaging in a dangerous and damaging false economy - saving money on quality preventative healthcare for disabled children only to cost ourselves £billions in subsequent avoidable interventions. In doing so, we are failing children and families nationwide, significantly curtailing their opportunities and quality of life and ultimately putting them at risk of secondary complications including premature death.

In 2013 a working group met to discuss a paper which would try to establish the links between the poor equipment provision for disabled children and secondary health complications for those children. Working closely with The Centre for Economics and Business Research the group funded a paper which looked at the current system, how much is spent on equipment for disabled children at present, how much is spent on interventions for those children and how much could be saved on interventions should the correct equipment be supplied in a timely fashion. This document aims to summarise the paper, detail some case studies and contextualise it within the current disability services framework.

In June 2016 the DWP released new estimated figures of how many disabled children are in the UK, placing the figure at almost 1 million, a 33% increase in the population over the past 10 years.

“More than one in thirty children in the UK is disabled in some way.”

3.3%



Key Issues

More than one in thirty children (3.3%) in the UK is disabled in some way.

Specialist equipment, including wheelchairs, seats, communication aids, beds and postural support systems play 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 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, with just £200 million spent on equipment.

It would cost **£500 million 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. For example, Wakefield Study.**



Wakefield Study

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. 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 the preventative or reconstructive surgeries has fallen dramatically, with a commensurate reduction in demand for consultant appointments and pain management. The cost savings of reducing surgical intervention is dramatic, as are the savings in terms of the traumatic effect of surgical intervention on the individual and their family.

To recoup the cost of providing every disabled child with all the equipment they need secondary complications must be reduced by 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 £130 million 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 through better provision of equipment, this could provide savings of £470 million.

These estimated savings are likely to be conservative given the evidence that the population of disabled children with severe disabilities is also expected to increase in the future.

Case Studies

Case studies like the following suggest that improvements in equipment provision can engender improvements in outcomes.

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-rotational 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.

Connor's Story

Olivia is a five year old little girl with a diagnosis of CDKL5, a genetic disorder which is thought to be linked to Rett's Syndrome and Autism. As a result Olivia has severe epilepsy, global developmental delay, hypertonia (low muscle tone or floppiness), left sided weakness and severe learning difficulties. Olivia also has dysphagia (swallowing difficulties) and due to ongoing aspiration pneumonias (infection caused by food going down 'the wrong way'), is now fed via gastrostomy (a tube directly into her stomach). However, maintaining correct alignment is of great importance to reduce the incidence of these respiratory complications.

Without support, Olivia's low tone means that she finds it hard to maintain an upright posture. When tired, she adopts a slouched posture with posteriorly tilted pelvis, abducted and externally rotated legs, and she leans over to her left side. Olivia's head control is good, but her sitting balance is not fully developed. Without support from a seating system Olivia, needs to use her arms for support, reducing her ability to explore and learn from her environment. The specialist seating system meets the complexities of Olivia's needs and offers the balance between stability and active movement. Her mum loves the tilt-in-space option for two reasons - when tilted prone, Olivia can step into the seat with help, and the supine option works well to administer her epilepsy medication when she has a seizure.

Olivia's Story

Summary

Essentially, this paper looked at the economic benefits of getting the right equipment to the children who needed it and how this may impact on their health and wellbeing. However, this overall positive impact on the economy is likely to be much greater if consideration is given to 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. It must also be looked at in context with how we support older disabled people. If we can get equipment provision right for children, who grow quickly and whose needs change on a transient basis, then equipment provision for adults should follow suit.

Getting it right for
children now should
lead to a reduced
requirement in the
adults of the future.