



Enabling Potential – Achieving a New Deal for Children with Cerebral Palsy

CONTENTS

Foreword from the Inquiry Chair	4
Foreword from the Chair of Action Cerebral Palsy	5
Executive Summary	6
Background	6
Key findings	6
Overview	7
Summary of recommendations	7
About the Inquiry	10
Process and Progress	10
Family Survey	10
About Cerebral Palsy	11
Definition and prevalence	11
Symptoms	13
Neuroplasticity and early intervention	14
Risk Factors and diagnosis	15
Our Findings	16
1) The need for early identification, assessment and intervention for children with cerebral palsies	16
2) The role of specialist educational support in helping children with cerebral palsies to develop their potential	24
3) Support and professional development for education and healthcare workers	30
4) Integrating health and educational support and ensuring a whole child approach	31
Appendix – Key Family Survey Results	33

Foreword from the Inquiry Chair

When first elected as an MP, I was very clear that I didn't want to be defined by the fact that I had cerebral palsy. Nothing could be worse than being pigeon-holed. My interests stretched from foreign affairs to transport policy and beyond –and I was the MP for Blackpool North & Cleveleys, with all the local issues I needed to focus on there as well.

So, why, five years later am I now writing an introduction to a report on provision for children with cerebral palsy? Some might argue I haven't achieved my goal. I would counter that by saying that any MP quickly realises how parents of children with disabilities struggle within an often adversarial system to do the best on behalf of the children they care for. In a constituency like mine, which has patches of severe deprivation, I am even more conscious that not every parent has the capacity to tackle a system which can at times ignore the real needs of a child.

I am also acutely conscious that whether I want to be defined by my cerebral palsy or not, for many people out there with CP, the fact that I have achieved my ambition of becoming an MP is evidence that others with CP can also set their sights high, and that parents both *can* and *should* be ambitious for their children to achieve, whatever that achievement may mean in an individual context.

So when Action CP approached me to chair their enquiry into provision for children with cerebral palsy, the only possible answer was 'yes'. And I have been both honoured and humbled to listen to the evidence of parents and professionals alike at the frustrations they often find with the system. In addition, this Parliament has seen the passage of far-reaching reform of provision for all children with special educational needs. Reducing the adversarial nature of securing support, and dismantling the barriers between health and education, have been two of the key principles at the heart of the reform. Even the Act's staunchest proponents acknowledge that the proof of the Act's success will only be visible once implementation is well under way, and when Education, Health & Care Plans are enabling parents to access the right support for their individual child, whichever local authority that specialist school may be in.

I also hope that we will see a much greater understanding of the importance of securing early diagnosis of cerebral palsy insofar as it is clinically possible, given that 0-2 are the 'golden years' for ensuring that neurological development can take place to help mitigate the impact of CP.

I would like to thank my colleague Mark Hoban MP for his invaluable support during the inquiry, with his knowledge of his own local provision at the Rainbow Centre. Additionally, the Minister responsible for the landmark Act, Edward Timpson, has been a stalwart supporter of the inquiry, and been an immense asset, as has the Secretary of State Nicky Morgan.

Along with the member groups of Action CP, I hope this report is but the first step in the greater recognition of CP as a condition, and in the potential of every child with CP to make remarkable progress in achieving their own goals if they can access the right support, which we all know is out there.

Paul Maynard MP
Blackpool North & Cleveleys

Foreword from the Chair of Action Cerebral Palsy

How can we substantially improve the lives for the estimated 30,000 children in the UK with cerebral palsies?

This is the question that the fifteen specialist centres that form Action Cerebral Palsy asked each other when discussing the inconsistent outcomes that exist for children with the condition across the UK. We realised that it would take a substantial movement for change to ensure that all children with cerebral palsies receive good quality early support. This is why we formed Action Cerebral Palsy: to start a movement, to shine a light on a condition which remains poorly understood and under-resourced.

We are delighted that Paul Maynard has provided such valuable support to that movement and has agreed to chair this Parliamentary Inquiry into cerebral palsies. As an individual with personal experience of the condition, Paul has brought a level of sensitivity and empathy to the inquiry that we have all greatly valued.

This inquiry has been enlightening. Although we have confirmed that there are areas of very good practice across both the public and voluntary sectors, we have also found that there are widespread challenges. We are learning that only a small proportion of the 1,800 children born with cerebral palsies every year receive the early and intensive intervention that can genuinely transform their lives. This is partly a result of poor understanding of the condition, partly down to insufficient proactivity in assessment and diagnosis and partly a result of insufficient resourcing of educational and therapeutic services at the most critical time of the child's life.

That we undermine the futures of children with cerebral palsies in the UK through under-investment is undeniably a waste of their potential but it is also a waste of the state's resources during the life of each individual. Early, intensive intervention is a high-yielding social investment that should be the norm, rather than the exception.

I sincerely thank all those who have been involved in the inquiry, whose contributions are recorded on the back page of this report. Action Cerebral Palsy will continue to campaign to ensure that children with cerebral palsies are given the very best start in life. This is a beginning, not an end.

Amanda Richardson
Chair, Action Cerebral Palsy
January 2015



Executive Summary

Background

This report outlines the findings of a parliamentary inquiry into the cerebral palsies, the overall aim of which has been to identify policy changes that could help the 30,000 children in the UK with cerebral palsies to achieve their full potential in life. The inquiry was launched in April 2014 by Paul Maynard MP, Chair of the Young Disabled Persons APPG, with the support of Mark Hoban MP, former Minister of State in the Treasury and Department of work and pensions.

The inquiry, which was run by Action Cerebral Palsy, has received almost 300 individual submissions from education and health professionals, those living with cerebral palsies and their carers, charities and other organizations with an interest in cerebral palsies and officials from the Department for Education.

The inquiry has sought evidence, views and experiences relating to:

- The need for early identification, assessment and intervention for children with cerebral palsies.
- The role of specialist educational support in helping children with cerebral palsies to develop their potential.
- Support and professional development for education and healthcare workers working with children and young people with cerebral palsies.
- Integrating health and educational support and ensuring a whole child approach.

Key findings

The inquiry has built a case for why more needs to be done to support children and young people with cerebral palsies – especially in the “golden years” post diagnosis for 0-2 year-olds when intervention is at its most effective, but also most absent.

The most prevalent reoccurring issues are:

- Insufficient specialist educational intervention available for 0-2s.
- Health professionals and parents are unaware of what is available.
- This lack of awareness leads to late diagnosis and missed opportunities for early intervention.

The inquiry has found a pressing need for a Government backed awareness raising exercise, so if one of the cerebral palsies is diagnosed, parents are made aware of the options available to them immediately.

Parents informed the inquiry that they become the experts on their child’s cerebral palsy and that uninformed professionals are often an obstacle to accessing the best support available.

The recommendations in this report set out how we can raise awareness about the cerebral palsies and, with a new approach, transform the lives of children whose potential is left unfulfilled.

Overview

Encouragingly, the evidence heard by the inquiry demonstrated that there is a great deal of consensus for change across a broad range of stakeholders. The inquiry revealed:

- Areas of very good practice exist across a range of providers (within the NHS, in voluntary sector specialist organisations and in some local authorities and schools).
- There was a widespread recognition that outcomes are extremely variable for children with cerebral palsies and their families across the UK.
- This is the result of the substantial number of agencies involved in the creation and implementation of policy (the Departments for Education and of Health, NHS England, NICE, local authorities, voluntary sector organisations and individual schools).
- The delegation of policy and funding to local bodies has created widely differing standards of provision across different services and in different areas of the country.

The UK lacks a common sense of what good should look like for children with cerebral palsies and their families. This parliamentary inquiry has identified many specific improvements that can and should be made, but it is critical that any approach to policy in this area engages the broad range of stakeholders that exist within the field of cerebral palsy.

Our recommendation for a multi-disciplinary taskforce to take forward the findings of this report and to establish and implement a national strategy for children with cerebral palsies, is paramount.

Without that breadth of engagement and the establishment of national minimum standards, some specific local improvements will probably be seen, but the fundamental issue of widely varying outcomes for children with the condition will remain unaddressed.

Summary of recommendations

1) The need for early identification, assessment and intervention for children with cerebral palsies

The arguments for early, intensive, repetitive and task specific intervention in young children with cerebral palsies are now well documented. High levels of early neuroplasticity provide a unique and urgent opportunity in the life of a young child with a cerebral palsy to make a meaningful impact on their future life potential. However, too often those opportunities are being missed. Assessment and diagnosis is not happening quickly enough (often hampered by relatively low levels of awareness among generalists and a prevalent ‘wait and see’ diagnostic approach). Therapeutic input is often not put in place until a diagnosis is obtained and that input, when it arrives, is often lacking in quantity and therefore intensity. This is not to say that the service that children and families receive is comprehensively poor – our survey of families demonstrated that there are many examples of excellence within the NHS. But there is quite clearly a very wide disparity of outcomes for children and families and this should be addressed.

Our survey of families also identified challenges with respect to signposting, support and counselling for parents before, during and after a diagnosis of cerebral palsies for their child. The inquiry heard comparisons between the experience of a newly diagnosed cancer patient (and the detailed information, support and extensive multi-disciplinary resources made available to them) and the

far sparser resources available to the family of a newly diagnosed child with cerebral palsies. The information and support available to such families and the signposting to appropriate services is often poor. Too many parents' experience is that they are left to fend for themselves and to work out the best provision for their child with little specialist input and advice.

The inquiry also identified a need for more and better coordinated research and the need for an appropriately anonymized national CP register to facilitate that research.

The recommendations under this first theme of the inquiry are detailed on pages 22-23 and include:

2) The role of specialist educational support in helping children with cerebral palsies to develop their potential

1. Nationally agreed protocols for early identification, assessment, diagnosis and intervention
2. National minimum standards for multi-disciplinary therapy availability and input
3. Improved statutory/voluntary sector collaboration
4. Improved signposting and support for families
5. Greater funding for, and better coordination of, research into the cerebral palsies in the UK

The evidence heard by the inquiry demonstrates that although there are cases of excellent special educational provision for children with cerebral palsies, (typically, but not exclusively, in the voluntary and independent sector), outcomes are too varied and many children are being failed by a system that is typically too generic in its approach. Specifically, provision for children and young people with cerebral palsies too often focuses on their physical challenges (and therefore the installation of ramps, handrails and lifts) rather than the other developmental challenges and barriers to learning that they face. Educational provision for children with cerebral palsies must be more holistic and consider their broader sensory, motor, social, communication and conceptual challenges. Much more needs to be done in the near term to ensure that children and families can access specialist, and typically voluntary sector, provision rather than being restricted to an inadequate generalist approach that will fail the child and the family and cost the state more in the long run. Over time, much more can be done to improve the skills of generalist providers by encouraging more collaboration with and training from existing specialist voluntary sector organisations.

Our specific recommendations are detailed on pages 28-29 and include:

1. Improved training and best practice guidelines for clinical and educational practitioners working with children and young people with cerebral palsies
2. Improved access to specialist provision for families of children and young people with cerebral palsies
3. A greater focus on active sensory motor learning in the curriculum
4. Recognition of the breadth of needs of children with cerebral palsies
5. Greater sharing of expertise between statutory and voluntary sectors, generalists and specialists
6. Improved signposting, minimum standards and enhanced funding streams from birth onwards to ensure local authorities can provide early intensive intervention and high quality integrated education provision to children and young people with cerebral palsies

3) Support and professional development for education and healthcare workers

The third theme within the terms of reference of the inquiry asked witnesses to consider potential improvements in the way that education and healthcare workers working with children with cerebral palsies could receive specialist training, development and support to help them in that work. These were issues that were covered quite comprehensively under the first two themes of the inquiry. Our recommendations are outlined on page 30 and include:

1. Improved awareness of cerebral palsies among both medical generalists (GPs and health visitors) and those working in schools (SENCOs, teachers, TAs and school-based therapists)
2. Improved training for (and numbers of) therapists trained to work with children and young people with cerebral palsies
3. Improved training for parents

4) Integrating health and educational support and ensuring a whole child approach

The inquiry warmly and unanimously welcomed the intent behind the Children and Families Act and the SEND reforms. However, there was also a widespread recognition that the changes could only be properly judged on their implementation, rather than on their intent. There was a great deal of scepticism (not least from parents who have faced protracted battles to get the provision they feel their children need) that the new system will continue to be dominated by funding shortages and will therefore be just as adversarial and ineffective in terms of outcomes as the old one. There was a great deal of concern that proper implementation of the Act and the SEND reforms will require a significant change of mindset within local authorities, a change that can probably only be achieved through more appropriate levels of funding.

That said, there is room for optimism given the clear commitment from all the stakeholder groups that gave evidence to this inquiry to work together to ensure that the reforms are implemented as intended, particularly (in relation to this inquiry) for children with cerebral palsies.

With that implementation in mind, we recommend the formation of a multi-disciplinary taskforce on cerebral palsies, comprising representatives from the Department for Education and Department of Health, local government, NHS, schools and voluntary sector organisations to:

1. Take forward the findings of this report
2. To develop a national strategy for children and young people with cerebral palsies, and
3. To ensure its implementation.

About the Inquiry

Process and Progress

In April 2014, with the support of Action Cerebral Palsy, Paul Maynard MP, Chair of the Young Disabled Persons APPG, launched a special inquiry with the aim of identifying the policy changes needed to help children with cerebral palsies achieve their potential.

The inquiry has sought evidence, views and experiences relating to:

- The need for early identification, assessment and intervention for children with cerebral palsies.
- The role of specialist educational support in helping children with cerebral palsies to develop their potential.
- Support and professional development for education and healthcare workers.
- Integrating health and educational support and ensuring a whole child approach.

The inquiry has sought evidence from a range of stakeholders, including education professionals, health professionals, those living with cerebral palsies and their carers, charities and other organizations with an interest in cerebral palsies, as well officials from the Department for Education and the Department of Health.

The inquiry has hosted four oral evidence sessions in the Houses of Parliament, which included evidence from parents and from education practitioners, health professionals, research professionals, legal professionals and Government officials. It has also gathered evidence from parents of children with cerebral palsies through a survey conducted during June and July 2014, to which 240 families responded.

The report is based on the evidence received and is intended as a basis for agreeing a way forward with Government and achieving the better outcomes that children with cerebral palsies undoubtedly deserve.

Family Survey

The Family Survey was conducted in June and July 2014 using a web-based survey tool and we were delighted to receive well over two hundred responses. We are very grateful in that regard to Scope, who kindly issued a number of calls for evidence across their network. Detailed results of the survey are attached in the Appendix and individual data (both qualitative and quantitative) is included within the body of this report to illustrate and elaborate some of the specific findings of the inquiry.

About Cerebral Palsy

Definition and prevalence

Cerebral palsy is an umbrella term for a group of motor disorders caused by damage to the immature or developing brain that occurs before, during or immediately after the birth of the child. With a UK incidence rate of around 1 in 400 births, or 1800 children per year, these conditions can affect those from all social backgrounds and ethnic groups. The conditions are the most common physical disabilities in childhood with an overall level of prevalence that has remained unchanged for sixty years (McIntyre et al, 2011)¹.

At some point very early in life, either while a baby is still growing in the womb, during birth or shortly after, something happens to interfere with the normal development of the brain or to injure the brain tissues. This is called cerebral palsies. It can affect children from all social backgrounds and ethnic groups. Although often considered a form of physical disability, it typically results in a range of impairments for the individual:

“Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsies are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems”. (Rosenbaum et al. 2007)²

These factors may present in varying degrees, and no two children will be affected in exactly the same way or to the same degree.

Cerebral palsy can be classified based on the predominant neurological findings³:

SPASTIC CP	Bilateral Spastic
	Unilateral Spastic (hemiplegia)
DYSKINETIC CP	Dystonic
	Choreo-athetotic
ATAXIC CP	

In all types of cerebral palsy an abnormal pattern of movement and posture is apparent. The condition is described by the way in which the lesion affects the messages to the muscles, as determined by the area of the brain affected:

¹ McIntyre S., Morgan C., Walker K., Novak I., (2011); *Cerebral Palsy - Don't Delay*, Developmental Disabilities Research Reviews 17:114-129

² Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, et al. Proposed definition and classification of cerebral palsy, April 2005. *Dev Med Child Neurol*. Aug 2005;47(8):571-6

³ SCPE Collaborative Group. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Developmental Medicine and Child Neurology*. 2000;42:816-24.

- **Spastic cerebral palsy**
This is caused by damage in the cerebral cortex of the brain. It is characterised by stiff, increased muscle tone and tightness which affects the way in which joints move. This makes movement hard work and spasticity can be increased with effort, anxiety and posture.
- **Dyskinetic or dystonic cerebral palsy**
This is due to damage in the area of the brain called the basal ganglia that affects coordination, muscle tone and control of movement. The children have difficulties with control of posture for sitting and standing. The unwanted movements can increase on effort, excitement or anxiety. Speech and eating may also be affected as the involuntary movement and control, can affect the mouth, lips and tongue.
- **Ataxic cerebral palsy**
This is a relatively rare form of cerebral palsy and may affect less than 10% of the cerebral palsy population. The part of the brain affected is called the cerebellum and it is this part of the brain that regulates and co-ordinates movement and is responsible for balance. All four limbs and trunk are usually affected. Children with this type of cerebral palsy have poor sensation of balance and often stagger when walking. They may also have a tremor as they intend to carry out a movement.
- **Mixed type of cerebral palsy**
It is common for children to have features of more than one type of the condition and some children will have a description of their presentation that will highlight the main problems e.g. the child can have Ataxic cerebral palsy with some spasticity.
- **Worster-Drought Syndrome**
This is a type of cerebral palsy that affects the nerves and muscles needed for speaking, eating, drinking and swallowing.

Whilst the above definitions describe the classification of the cerebral palsies, they do not give a clear picture of the challenges or nature of living with this condition. Although often described as non-progressive the effects of the cerebral palsies do change over time. Much of current 'treatment' focuses around the management of symptoms rather than the impact of these on child development, maturation and neuroplasticity.

As cerebral palsy affects a child from birth onwards, the implications on the developing child cannot be ignored. During the formative years the central nervous system develops at a rapid pace enabling the child to learn, explore and connect with their social environment. It is during these crucial years that the ability to 'learn' is developed. Children with cerebral palsies will be hindered, to varying degrees, in the process as they battle to learn fundamental skills related to symptoms. Therefore cerebral palsies should to a significant extent be considered as a problem of 'learning' rather than a problem of functioning or communicating.

Children with cerebral palsies require time, opportunity, external expectation and specialized teaching to develop the underlying neurological structures required to promote learning and development. Only then can the true potential of the child be recognised.

Symptoms

Damage to the central nervous system can cause the following effects:

- Impaired transmission of information from the tactile, vestibular, proprioceptive, visual, auditory and olfactory systems leading to hypo or hyper sensitivity and/or modulation problems.
- Retained primitive reflexes such as asymmetric tonic neck reflex, Moro, startle, primitive stepping.
- Abnormalities of muscle tone; low, high, fluctuating and rigidity.
- Delayed or disturbed righting and balance reactions.
- ADHD symptoms (Epipage study 2009, 2002).
- Short and long term memory deficits (Woodward et al, 2011; Tinelli et al 2014).
- Visual-spatial and navigation dysfunctions (Pavolva et al. 2007; Fazzi et al, 2009).

In turn, these issues can affect:

- Cognition resulting in learning difficulties and language/ communication impairment, either as a result of low cognitive functioning and/or as a result of restricted access to the learning experiences of normally developing infants and young children.
- The physical structures of vision, hearing and speech and language and/or the processing of information from these functions.
- Sensory and perceptual processing which can lead to difficulties with motor planning and organisational skills.
- Health and well-being, eating and drinking, nutrition, digestion, respiration, epilepsy and other medical disorders.
- Emotional and social development, mental health.

The spectrum of disability as a result of cerebral palsies can range from mild physical disability with no other issues and normal cognitive functioning to very complex and severe disability affecting all aspects of function.

In summary, the cerebral palsies encompass a number of neurological disorders which can affect all aspects of development in the young child. Therefore, cerebral palsies should not be considered as just physical disabilities, and when non specialists make this assumption, the broader effects of the condition are missed and not acted upon as they should be. Whilst we cannot change or reverse the initial damage to the brain we can and should influence and address the consequences of that damage and do it before the effects listed above compromise the ongoing development of the child in their crucial early years.

Neuroplasticity and early intervention

Although the cerebral palsies cannot be cured, early intervention and intensive therapy can substantially mitigate its impact. With appropriate intervention, the weight of recent neuro-scientific research suggests that high levels of neuroplasticity in young brains can be harnessed, allowing undamaged parts of the brain to be retrained to take over some of the functions of the damaged parts.

Neuroplasticity is an umbrella term which refers to the way that neural pathways and synapses develop, interconnect and form new connections. Neuroplasticity allows for environmental influences to change the way the brain makes connections. It is particularly important in relation to the cerebral palsies and brain injury because it allows for “re-mapping” of neural pathways where there has been damage to existing pathways.

Infancy and early childhood is a critical period for neuroplasticity^{4,5,6}. It is a period in which neuroplasticity is at its most active and consequently the developing brain most responsive to sensory motor experience and environmental learning. Neuroscientific research has shown that changes to the brain as a result of neuroplasticity can change the brain’s physical structure and the way it works. Research is now engaged in demonstrating how the brain can and does change during the critical period of early childhood. Neuroplasticity is therefore the key factor that supports the scientific basis for intervention for children with neurological damage with goal-directed, experiential programmes in order to mitigate the functional effects of the initial damage. Moreover, the increasing body of research on neuroplasticity suggests that individualised, repetitive, task specific, intensive and incrementally challenging interventions for cerebral palsies should commence very early in life, in the first two years, whilst the brain is most active^{7,8}.

Studies emphasize the crucial role of early sensorimotor experience and suggest the critical importance for early interventions and sustained activity in children and infants with cerebral palsies to hopefully restore sensorimotor functions or at least prevent further degradations.

Through early intervention, these infants and young children can be helped to develop more typical posture, muscle tone, and movement patterns. Their motor learning at this early stage will form the bedrock of the independence they can achieve in later life. Early intervention is also a high-yielding social investment, delivering positive outcomes for those children and their families: physical and emotional health and wellbeing, lower levels of stress, improved social development and a reduced need for more complex and costly interventions in later life. Children who receive early intervention are substantially more independent than they would otherwise be, significantly reducing the costs of their future education and care that would otherwise fall both on the state and the voluntary sector.

⁴ Pascual-Leone, A., Freitas, C., Oberman, L., Horvath, J. C., Halko, M., Eldaief, M. et al. (2011). *Characterizing brain cortical plasticity and network dynamics across the age-span in health and disease with TMS-EEG and TMS-fMRI*. *Brain Topography*, 24, 302-315

⁵ Basu, A. (2014), *Early intervention after perinatal stroke: opportunities and challenges*, *Developmental Medicine & Child Neurology* 2014, 56: 516–521

⁶ Herskind, A., Greisen, G., Nielsen, J., (2014), *Early identification and intervention in cerebral palsies*, *Developmental Medicine & Child Neurology* 2014 Review, 1-8

⁷ McIntyre S., Morgan C., Walker K., Novak I. (2011), *Cerebral Palsy - Don't Delay*, *Developmental Disabilities Research Reviews* 17:114-129

⁸ Sgandurra et al, (2014), *Home-based, early intervention with mechatronic toys for preterm infants at risk of neurodevelopmental disorders (CARETOY): a RCT protocol*, *BMC Pediatrics* 2014, 14:268

Risk Factors and diagnosis

Risk factors which might result in cerebral palsies are:

- Interruption to the blood flow or oxygen to the brain before, during or after birth
- Maternal disease, infection or pre-eclampsia during pregnancy
- Haemorrhages
- Drug/alcohol abuse by mother
- Heart/respiratory distress
- Blood group incompatibility
- Prematurity
- Multiple births
- Low birth weight
- Maternal history of miscarriage or still birth
- Genetic predisposition
- Post natal infection, stroke, accidental or non-accidental injury

Studies consistently demonstrate (Badawi et al., 2005⁹; Wu et al., 2006¹⁰; McIntyre et al., 2011¹¹) that these early risk factors exist in perhaps just over half of all children who go on to be diagnosed with cerebral palsies. Around 30-40% of those children are born prematurely and another 15-20% experience some form of neonatal encephalopathy shortly after birth. Where such clear risk indicators exist, medical professionals are typically alert to the possibility of developmental problems for the child. Diagnosis tends to occur quite early in the child's life and follow-up typically follows as a matter of course.

However, in the remaining 40-50% of children with cerebral palsies, risk factors are not evident and it typically falls upon parents to raise developmental concerns with their GP. Experiences vary in such cases but anecdotally, health professionals have typically adopted a “wait-and-see” approach in such cases, often resulting in delayed diagnosis and little or no intervention during the period of most rapid neural development (McIntyre et al., 2011¹¹). Given the critical importance of early intervention, families' experiences of assessment and diagnosis have formed a key part of this inquiry, as outlined in the *Findings* section of this report.

McIntyre et al in particular highlight models of assessment that are capable of earlier and more accurate diagnosis of cerebral palsies, such as the *Qualitative Assessment of General Movements (GMs)* and the *Hammersmith Infant Neurological Assessment*. Such models and the potential for their wider application within UK health practice were brought to the attention of the inquiry by health professionals.

⁹ Badawi N., Felix J., Kurinczuk J., et al. 2005. *Cerebral palsies following term newborn encephalopathy: a population-based study*. Dev Med Child Neurol 47:293–298.

¹⁰ Wu YW, Croen L., Shah S., et al. 2006. *Cerebral palsies in a term population: risk factors and neuroimaging findings*. Pediatrics 118:690–697.

¹¹ McIntyre S., Badawi N., Brown C., et al. 2011. *Population case-control study of cerebral palsies: neonatal predictors for low-risk term singletons*. Pediatrics 127:e667–e673.

Our Findings

1) The need for early identification, assessment and intervention for children with cerebral palsies

THE CASE FOR NEUROPLASTICITY AND EARLY INTERVENTION

As noted elsewhere in this report, the arguments for early, intensive, repetitive and task specific intervention that can harness early neuroplasticity in young children are well documented (McIntyre et al., 2011¹²). Those arguments were substantially reinforced by specialist evidence provided to the inquiry. There was widespread consensus among clinical specialists and practitioners that early plasticity in children with cerebral palsies provides a unique and urgent opportunity in which intensive intervention can make a real difference to a child's future potential. Professor Ramnani, Professor of Neuroscience at Royal Holloway College, told the inquiry that the critical period of neurodevelopment takes place during early childhood and that early postnatal interventions for children with cerebral palsies are therefore likely to play important roles in allowing the nervous system to develop as normally as possible. Betty Hutchon, Head of Children's Occupational Therapy at the Royal Free Hospital, referred the inquiry to research published by Professor Janet Eyre of the University of Newcastle which demonstrates that plasticity is at its most prevalent in the first three months of life. There was a broad recognition that the current protocols for identification and diagnosis of cerebral palsy mean that the majority of children with the condition miss out on intensive intervention during this critical period of maximum plasticity.

"One of the most significant features of cerebral palsy which sets it apart from other special educational needs cases is the need for early and intensive intervention which can lead to significantly better outcomes for children and concomitant savings in costs to society as a whole".
Nageena Khalique, Head of Public Law, No5 Chambers.

However, there was also recognition that further research is needed to understand the nature of critical periods of development in early childhood and the types of interventions that can harness the different forms of plasticity during different stages of development. There was strong support for more resources to be made available nationally to facilitate such research and for it to be better coordinated between research groups. However, in addition to the need for more resources, the inquiry also heard strong arguments for more robust data to be maintained about disabled children and young people. Dr Karen Horridge, a leading paediatrician specializing in childhood disability, outlined the lack of such data in the UK and internationally and the opportunities that improved data could bring to improved outcomes for children with cerebral palsies. There are strong arguments for some form of national CP register, perhaps similar to that which exists in Australia, although the inquiry also heard cogent arguments for any data to be appropriately anonymized to ensure that it could not be used to discriminate against individuals with the condition.

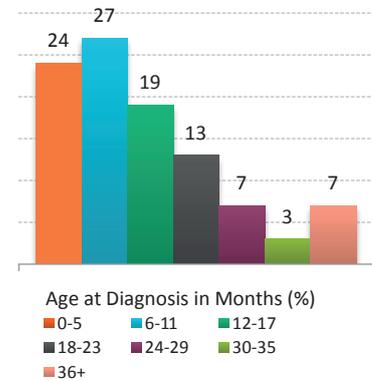
¹²McIntyre S., Morgan C., Walker K., Novak I. (2011), *Cerebral Palsy - Don't Delay*, Developmental Disabilities Research Reviews 17:114-129

ASSESSMENT, DIAGNOSIS AND REFERRAL

Evidence from Families

This parliamentary inquiry has, through both the oral evidence session and our family survey, sought to examine the experiences of the families of children with cerebral palsies and to identify whether more can be done to improve the way in which babies and toddlers with the condition are assessed and diagnosed.

Our family survey presented a very mixed picture in assessment and diagnosis. Although 83% of parents reported that they had received a diagnosis before the age of 2, there was a meaningful spread of outcomes within that period. In addition, as might be expected, we found that children who were identified as having more complex needs tended to be diagnosed earlier.



46% of parents felt that the process of diagnosis had worked as it should but 54% felt that it had not.

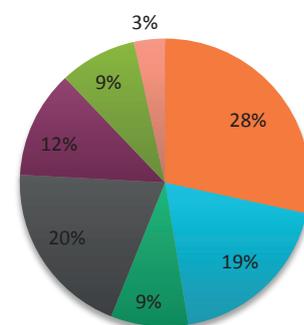
“Parents of children with CP just need more information. We need to know what we are facing, what help and support there is out there. We have been pretty much totally reliant on other parents who are further along the CP journey than us. This shouldn’t be the case.”
Parent testimony

The results suggest that some of that dissatisfaction results from the time taken to obtain a diagnosis and some from the lack of specialist support and advice. 54% of parents receiving a diagnosis before their child was 18 months old felt that the process had worked as it should, compared to only 25% of those receiving a diagnosis after 18 months.

However, much of the dissatisfaction with the process of diagnosis appears to be the result of a lack of specialist support and advice before, during and immediately after diagnosis. We found that prior to and during the process of diagnosis, 58% of parents found it difficult to find such support while only 25% found it relatively easy. Immediately after diagnosis, 47% of parents still found it hard to obtain the help they needed, compared to 33% who found it relatively easy. It is clear that there is a widespread lack of support and information for families before, during and after diagnosis, at a time when they most need that help.

We asked parents: “What suggestions would you make to improve the process of diagnosis?” and were able to group responses into a number of distinct headings. By far the most common complaint was that parents did not feel listened to; that health professionals had not taken them seriously when they raised concerns about their child’s development. A number also complained at

Suggested Improvements in Diagnosis



- Concerns not taken seriously
- Speed of referral / diagnosis
- Support and counselling
- Honesty
- Information
- Communication / Protocols
- Expertise

the amount of time either to achieve a referral or to obtain a diagnosis, echoing the findings outlined above. Many parents felt that health professionals had been unwilling to give an honest assessment

of their child's condition and also that having received a diagnosis there was little information, support and counselling to help them. A number of parents also suggested that communication between health professionals had been poor and that there could be better, and more joined-up, protocols within the process of diagnosis.

We were also able to isolate some geographic anomalies in diagnostic outcomes for children and families. Typically, we found that satisfaction with the process of diagnosis and with the quality and availability of NHS follow-up provision was higher in cities than in other urban or rural areas and it is perhaps not an unreasonable assumption that the larger teaching hospitals in the UK's major cities are better resourced and skilled to work with children with cerebral palsies and their families. In addition, although our sample was too small to achieve full clarity at a local authority level, we did find hotspots of good and less good performance. For instance, 4 out of 5 of parents from Birmingham and 4 out of 6 in Herefordshire were satisfied with the process of diagnosis compared to 4 parents in each of Bradford, Chiltern, Mid Sussex and Milton Keynes who were dissatisfied.

"There needs to be a greater recognition of the utter darkness that families find themselves in at this time - a diagnosis of CP can be devastating and simply providing a once a month physio appointment and OT appointment doesn't go anywhere near to providing the support that families need to help themselves and their precious child to begin to adjust to the life ahead of them." Parent testimony

It is clear that in many cases, diagnosis is rapid (particularly for those children where the risk factors are very evident) and that parents feel well supported. Our findings make it clear that there are genuine centres of excellence within the NHS where the process works. However, our findings also demonstrate a significant number of cases where parents have had to fight to be heard and to achieve the referrals their child needed and that many have then had little access to specialist information and advice during and post-diagnosis. In these cases, families have gone through unnecessary hardship (on top of the emotional trauma of knowing that something is wrong) and the opportunity for early intervention has either been missed entirely or at least severely reduced.

Evidence from Practitioners

Evidence from families on their experiences of assessment and diagnosis were clearly supported by the expert evidence we received from practitioners. Evidence from Dr Christopher Verity, Consultant Paediatric Neurologist at Addenbrooke's Hospital in Cambridge, supported the findings outlined earlier in this report (Badawi et al., 2005¹³; Wu et al., 2006¹⁴; McIntyre et al., 2011¹⁵) that although diagnosis tended to be rapid in children with obvious risk factors, there were substantially greater challenges in achieving a timely diagnosis in the many cases where problems are not apparent around the time of birth. In such cases, some may be diagnosed by about 6 months of age but if developmental problems are more subtle, the diagnosis may not be until a year of age or later.

¹³Badawi N, Felix JF, Kurinczuk JJ, 2005. *Cerebral palsies following term newborn encephalopathy: a population-based study*. Dev Med Child Neurol 47:293–298.

¹⁴Wu YW, Croen LA, Shah SJ, 2006. *Cerebral palsies in a term population: risk factors and neuroimaging findings*. Pediatrics 118:690–697.

¹⁵McIntyre S, Badawi N, Brown C, 2011. *Population case-control study of cerebral palsies: neonatal predictors for low-risk term singletons*. Pediatrics 127:e667–e673.

There was a general recognition that although the use of MRI was important in the process of diagnosis, widespread use of MRI as a screening tool was inappropriate as it often fails to inform treatment, is invasive and frightening. Instead, there was a strong consensus that the best assessment and diagnostic approaches involved identification of abnormalities in movement and development, supported by the confirmatory use of MRI. Betty Hutchon provided the inquiry with compelling evidence for the use of the General Movements Assessment¹⁶ (GMs) as a tool for predicting cerebral palsies in very young children from the preterm period until 20 weeks post term age. GMs is quick, family-friendly and non-invasive and has been shown to be 98% reliable in predicting cerebral palsies. Once this non invasive diagnostic tool has identified concerns, a rapid referral to a paediatric neurologist could follow.

“When people tell you it’s not possible to identify early, it’s just because they haven’t got the right tools”. Betty Hutchon, Paediatric Occupational Therapist

Although GMs is capable of improving the speed with which children with cerebral palsies are identified, assessments can only be conducted by a trained practitioner. While children with obvious risk factors around and about the time of birth are increasingly likely to be followed up in this way, children with less obvious signs of disordered development (who would benefit most from such an assessment) are far less likely to be assessed at this critical period of development. There was strong consensus among the practitioners giving evidence to the inquiry that GPs and health visitors are critical in helping to ensure rapid referral for an early assessment. It was commonly felt that awareness of the typical early signs of the cerebral palsies among GPs and health visitors should be improved and that there should be more consistent and well-signposted pathways for onward referral, both nationally and locally. The inquiry also heard that the Advisory Assessment Service that had been run by Scope (but which has now been discontinued) was a service that might sensibly be re-examined as a model of good practice. Within that service, parents were able to access a 2-3 day assessment carried out by an onsite multi professional team that would provide a detailed insight into the specific needs of their child and signposting to appropriate follow-on services. The inquiry heard that most of the specialist centres for cerebral palsies would be able to resource such a service if appropriate funding could be made available. A joined up assessment service of this kind carried out by a transdisciplinary team would be invaluable to parents as an independent assessment of their child’s needs in all areas which could be used to inform Education, Health and Care Plans.

There was strong consensus that parents should have good access to advice and support as soon as developmental issues are identified, on practical areas such as feeding and sleeping as well as on signposting to follow-on services and intervention. It was also agreed that parents should have access to sympathetic support and counselling at what is a challenging time for the family.

Practitioners also felt that there should be a bias towards referral, of giving parents with legitimate concerns the benefit of the doubt rather than subjecting them to the uncertainties of a “wait and see” approach. They should certainly not have to fight to achieve a referral, which practitioners acknowledged was quite often the case.

¹⁶Einspieler C., Marschik P., Bos A., Ferrari F., Cioni G., Prechtel H., 2012. *Early markers for cerebral palsies: insights from the assessment of general movements*. *Future Neurol.* (2012) 7(6), 709–717

There was also a strongly held view that effective early intervention should not wait for a formal diagnosis. In the words of Dr Karen Horridge, “Intervention does not need to wait for diagnosis to be confirmed and indeed, if intervention waits for specific diagnosis, the best window of opportunity to intervene in a way that makes the most positive difference may have been lost. Thus early therapy input to neonatal and special care baby units is essential, with careful, expert follow up of infants at high risk of evolving cerebral palsies so that interventions can begin without delay”.

EARLY THERAPEUTIC INTERVENTION

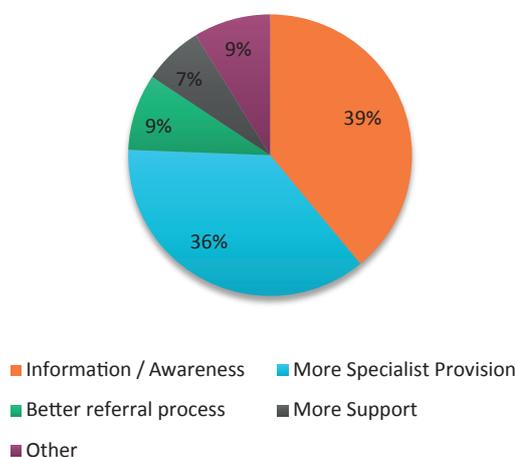
Evidence from Families

We asked a range of questions about the NHS services that families had contact with during their child’s early years (age 0-3). Predictably high numbers reported that they had seen a physiotherapist (94%), health visitor (81%), occupational therapist (76%) and/or speech and language therapist (71%). Relatively lower numbers had attended an NHS Children’s Centre (39%) or had contact with a special needs health visitor (17%).

In terms of that support in early years, the NHS scored relatively highly in terms of knowledge and expertise (with 74% of parents giving a rating of 3, 4 or 5 stars). However, parents were significantly less satisfied with the availability and intensity of NHS support during early years (with 79% of parents giving a rating of 1, 2 or 3 stars). From what parents have told us, NHS expertise is largely acknowledged and appreciated but parents are concerned and frustrated by the amount and availability of that skilled resource. In particular, parents tell us that local NHS therapists’ workloads are too high and that there is often little relationship between the complexity of a child’s needs and the amount of support they receive. Parents complain of significant turnover and posts being vacant for long periods of time, leading to inconsistency of provision.

By way of contrast, 72 (30%) of our respondents told us that their child had attended a specialist centre for children with cerebral palsies in our early years. Of these, 14 had attended PACE in Aylesbury, 8 had attended the Dame Vera Lynn Trust School for Parents, 5 had attended Megan Baker House in Herefordshire, 5 had attended The Bobath Centre in London, 4 had attended the Rainbow Centre in Hampshire and 3 had attended the Small Steps nursery in London. Respondents identified another 20 organisations around the UK, together with the Peto Institute in Budapest, as specialist settings that had provided support to their child. These settings are all specialist in working with children with neurological impairments, such as the cerebral palsies, providing expert and intensive intervention for young children. Most if not all of them work with the family as a whole, providing support and practical advice to parents as well as providing therapeutic input and access to early learning to the child itself. And virtually all of them are voluntary sector providers. Critically, parents rated the provision they received from those specialist centres extremely highly, 89% of parents giving a rating of either 4 or 5 stars.

Availability of and Access to Specialist Support



We asked parents what could be done to improve the availability of and access to specialist support for children with cerebral palsies in their early years and their families. Overwhelmingly, they told us that information on services should be more easily available, that NHS professionals should have more awareness of cerebral palsies and the follow-up options available and that there should be more counselling and support. A number of respondents suggested that there should be a more joined-up process of referral and advice, clearer pathways and ideally a key-worker to help families, particularly in the early stages post-diagnosis.

One parent made the critical, but often ignored, observation that the system is currently skewed in favour of families that are inherently more resilient and capable and that children from more vulnerable families are more likely to miss out. Parents also said clearly that there should be more specialist provision available, more specialist centres, more frequent access to specialist occupational therapy, physio and speech and language therapy support and more specialist health visitors. Some parents complained that NHS professionals were either unaware of existing specialist centres (particularly those in the voluntary sector) or reluctant to refer families to them.

“The unconscious question being asked by professionals when they are setting out their views on provision is “What can we provide within our limited resources to address the needs of this child as best as possible?”, which is very different from “What provision should be provided to best meet the needs of the child?” And then when the voluntary sector offers greater levels of support, they then find themselves in conflict as they seek to defend their recommendation, when really they should be embracing the extra and hopefully complementary therapy that this could provide”. Parent testimony

*“It shouldn’t have to be a fight to get what you need to meet your child’s needs, but it is, daily”.
Parent testimony*

Many parents suggested that there should be more collaboration between NHS professionals and voluntary sector specialists and also that there should be greater funding for voluntary sector providers. Many parents alluded to the postcode lottery that exists

for specialist input for children with cerebral palsies and related conditions. A number of parents suggested that more support should be available both pre-diagnosis and as the child gets older.

Evidence from Practitioners

Practitioners’ evidence to the inquiry about the availability and access to early support and intervention broadly supported the views of parents. There was a widespread consensus that there are examples of good practice but that there remains a postcode lottery for provision for children with cerebral palsies across the UK with significant variations of the quality of intervention. The inquiry heard that localism was often the enemy of consistent good practice and that a centralized approach to standards and protocols was likely to achieve better results than devolving all responsibility for deciding levels of provision to local authorities and CCGs.

There was widespread agreement that a multi-disciplinary approach is best for children with cerebral palsies but practitioners also echoed the views of some parents that the approach needed to be more joined up. Practitioners recognized the challenges for the family in dealing with a significant number of professionals from different disciplines and there were suggestions that a lead “developmental therapist” from one of the disciplines might help to provide a more accessible overall service.

There was also a strong sense that children with significant disability that nevertheless falls short of the most serious disability are particularly vulnerable within the current system. John de Bono QC, a barrister with significant experience of working with children with cerebral palsies and their families,

told the inquiry: “Children with the most profound needs are usually on the radar of social services and health services. It is the children of families who appear to be able to ‘get by’ who slip under the radar and who miss out on provision which might make a real and significant difference in the longer term”.

Practitioners also recognized that statutory therapeutic resources are too thinly spread in many regions to provide the required intensity of intervention. Christine Barber, Director of Therapy at The Bobath Centre for Children with Cerebral Palsy outlined typical levels of physiotherapy support per children aged 0-6 years in the UK (12 hours a year) and contrasted it with the levels in Canada (6.5 hours per month). There was also a recognition that enabling children with cerebral palsies to communicate early in their lives was critical and that more can be done in this important area. There was strong support for more resources to be made available to deliver more intensive therapeutic intervention – an investment that most practitioners argued would provide strong real financial returns given the greater ability, independence and potential that children with cerebral palsies would then be able to achieve.

In contrast, however, a number of the practitioners noted that a key positive difference between best practice in the UK and typical practice in many other European countries is that there is greater focus here on working with and through the parent, rather than just the child. There was a strong consensus that parents have a key part to play in helping to deliver therapy and warm support for the Schools for Parents model that exists within a number of specialist centres in the UK.

RECOMMENDATIONS

The evidence submitted by families to the parliamentary inquiry demonstrates clearly that outcomes for children with cerebral palsies are extremely variable. We found that the process of diagnosis worked as parents thought it should in about a half of cases and it is clear that there are centres of excellence around the country (in both the statutory and voluntary sectors) that are providing high quality follow-up and early intervention. However, in too many cases, diagnosis is occurring later than could otherwise be achieved and information and signposting for parents is severely lacking. There is not only a distinct postcode lottery for specialist services but also a lack of awareness of those services among health professionals and sometimes a reluctance to refer to them. Young children with, or at risk of having, cerebral palsies deserve a better and more consistent level of provision at a time that is critical for their development. In that context, we recommend:

1. **Nationally agreed protocols for early identification, assessment, diagnosis and intervention:**
The creation of a common standard set of nationally agreed protocols and pathways for early identification, assessment, diagnosis and intervention, to include:
 - a. A greater emphasis placed on the concerns of parents
 - b. A commitment to more rapid referral and elimination of the “wait and see” approach to assessment and diagnosis
 - c. The delivery of early therapeutic intervention as soon as issues are evident and in advance of formal diagnosis
 - d. More widespread use of the General Movements Assessment (GMs) and confirmatory use of MRI in achieving a swift diagnosis.

2. **National guidelines for multi-disciplinary therapy availability and input:** National guidelines for local authorities for multi-disciplinary therapy availability and input to help ensure that each child receives an appropriate amount of therapeutic support and that the current postcode lottery for provision can be meaningfully reduced. These minimum standards should differ according to the complexity of needs of the child but should ensure that all children (even those with relatively less complex needs receive the help they need to achieve their potential in life).
 3. **Improved statutory / voluntary sector collaboration:** Continuing focus on ensuring meaningful collaboration and commissioning between statutory health bodies and the voluntary sector at all stages of the process. This is envisioned within the Children and Families Act and recent NHS reforms but has yet to be seen in practice in most regions.
 4. **Improved signposting and support for families,** to include:
 - a. The widespread use of “lead developmental therapists” to lead engagement with each child and provide a single point of contact for families
 - b. A web resource with information for families outlining information on disordered development and the cerebral palsies, local services available and minimum standards they should expect from statutory services
 - c. Counselling
 - d. Proactive and timely advice on practical issues, such as feeding and sleeping.
 5. **Greater funding for, and better coordination of, research into cerebral palsies in the UK,** to include:
 - a. The development of an appropriately anonymised national CP register to enable improved research into the condition
 - b. Research into the optimal timing of early intervention, based on the highest levels of childhood neuroplasticity
 - c. Research into benefits of different types of intervention at different stages of development
 - d. A more highly developed understanding of the social investment return of early intervention (in terms of lower future costs of healthcare, education and social care).
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2) The role of specialist educational support in helping children with cerebral palsies to develop their potential

RECOGNITION OF CEREBRAL PALSY AS AN EDUCATIONAL ISSUE

While the cerebral palsies are clearly recognised medically as neurological conditions, educationally they are often simply labelled a physical disability and the child's impaired ability to learn is not addressed properly.

While the UK education sector appears to accept that children with visual impairments, hearing impairments or autism are likely to require highly specialist educational input, the same is not typically true for those with cerebral palsies. As one contributor put it "the education and upbringing of children with cerebral palsies is a non-subject". A recurring theme in the evidence to the inquiry was the lack of recognition by the education system and local authorities of the specific learning needs of children with cerebral palsies and that a "one size fits all" attitude prevails.

All too often, our educational system perceives the cerebral palsies as simply physical disabilities. In too many cases, we see the response to cerebral palsies (within an overwhelmingly inclusive and non-specialist system) focus too much on delivering a physically accessible environment (ramps, handrails and lifts) rather than a genuine understanding of the condition and a response to each child's specific needs. A child with a neurological condition such as a cerebral palsy will, in addition to their evident physical challenges, have extensive difficulties in other areas of development: communication, the ability to learn and to process information, self-care and independence, self-esteem, confidence and often mental health. These problems are typically overlooked or misunderstood in children with cerebral palsies and as a result the current prevalent approach prevents many from reaching their full life potential. As Professor Rosemary Varley, Division of Psychology and Language Sciences, University College London, commented, "Cerebral palsy suffers from its position at the intersection between health and education, and integration of both perspectives is critical in developing innovative services with potential for maximal outcomes"

Because the cerebral palsies are considered essentially physical and medical in nature, intervention within an educational setting is often left to therapists rather than ensuring a holistic approach to learning which recognises the inter-related challenges that sensory, motor, communication and conceptual learning difficulties present to a child with a cerebral palsy. Therapy is often delivered separately from the educational context, and without the intensity and targeted goal-orientated focus that is required to effectively harness neuroplasticity.

"We have helped many families in their 'fight' to secure adequate health, special education and social care for their children. At times provision and decision making has been so woefully inadequate and flawed as to represent a safeguarding issue necessitating judicial review by the courts. This should not be the case". Paula Barnes, partner, Moore Blatch

"The disordered motor development of the cerebral palsies may be complicated with co-existing disorders of learning, vision, hearing, communication, eating and drinking, behaviour, emotions, mental health, sleep and epilepsies" Dr Karen Horridge, consultant paediatrician (disability)

In particular, the vital importance of active sensory motor learning in the very young child which underpins all other functional skills (movement, play self-care etc.) is very rarely recognised in non-specialist pre-school or nursery settings. Children with cerebral

palsies will spend too long sitting in their wheelchairs with inadequate access to experiential play, when they should be supported to move in space and engage in high intensity sensory motor manipulation activities, so vital for early learning, motor development and musculoskeletal health.

ACCESSING SPECIALIST SUPPORT

Many families who have contributed to the inquiry have told of the long hard battle to secure appropriate educational provision for their child. Parents, who have been under extreme pressure from the birth of their child onwards, know only too well about the complex and multi-faceted nature of their child's needs. Yet many have then had to endure great difficulties in their search for the right level of educational support for their child. Phrases such as "constant battle" (in obtaining services between education and health) are common. One parent said that they had found dealing with education authorities a "profoundly isolating experience" and had been left "bitter and saddened by the whole experience" and fearing that "we will be forever fighting our corner to ensure [our son] gets what he deserves".

"We have been left feeling very bitter about the whole experience, and are now of the belief that we will be forever fighting our corner to ensure our son gets what he deserves. We feel very sad about this – the UK should be set up to make life easier for disabled people and their families." Parent testimony

"There is a huge variation in the quality and quantity of educational support [for children with cerebral palsies] depending on postcode and the ability of parents to fight for better provision." John de Bono QC

Many of these difficulties appear to have arisen because of a culture of short-term cost saving within local authorities. Parents complain that the local authority approach appears to default to the option that requires the least input with recommended actions being based on resources available rather than actual needs. There were examples of bias in favour of local authority provision from

professionals employed by the NHS and the local authority who were involved in statutory assessments, and of professionals being instructed by senior managers not to put their honest recommendations for input in writing, or in one parent's view "to toe the party line". Far from supporting parents to access specialist support, most local authorities spend vast amounts of money actively denying access to specialist support. The inquiry heard from a good number of parents and specialist centres that local authorities are using valuable resources to hire specialist barristers and solicitors to manage appeals to educational tribunals where the costs of this were likely to have covered much of the provision that the parents were seeking on behalf of their children.

Parents said that they wanted their children's educational needs to be assessed accurately by specialists who were experts in the cerebral palsies but that input and reports from independent specialist centres for children with cerebral palsies or other voluntary or charity agencies were not requested or ignored during the statutory assessment process.

As a result of these difficulties, many parents have had to use their own resources to seek out and self-fund specialist assessments, reports, input and equipment for their child. Where a child has been placed in settings in which their needs were not understood or met, parents have had to take on the role of co-ordinator and disseminate critical information to act in their child's best interest. This inevitably leads to high levels of stress and in some cases, to family breakdown (with its own evident financial and social costs). Parents have had to leave paid work in order to ensure that their child's educational and health needs are fully met.

SPECIALIST SUPPORT IN PRACTICE

The inquiry heard from a wide number of specialist centres working with children with cerebral palsies and their families, including the Bobath Centre in London and a variety of other specialist centres from across the UK. There was a strong consensus that during the early years of a child's life in particular, it is the parents as well as the child, who need education. Many specialist centres and providers of services for children with cerebral palsies across the UK (often in the voluntary/charitable sector) already work in partnership with parents to prepare their children for life at school, in the community and through the experience of daily tasks which are essential to the growth of motor, cognitive, social and communication skills. Parents are taught by a team of specialists how to enable their child to learn a range of essential foundation skills including motor, communication, and self-care skills, cognitive knowledge and understanding, function and how to develop their independence skills. The inquiry heard how the work of such centres results in parents being empowered to understand and appreciate their child's abilities and achievements, to have high expectations and to have the tools required to support their child's physical access and learning.

The inquiry heard from a wide variety of parents (both during the oral evidence sessions and from the survey) of the effectiveness of the Conductive Education approach for their child. Conductive Education teaches children with movement problems to learn actively to achieve purposeful movement which can then be applied throughout their daily living, in all situations. It is holistic and unified and it addresses all aspects of the children's development in an integrated way. Conductive Education teaches children to function despite their disability and helps them acquire the capacity and wherewithal to deal with the challenges they will meet on a daily basis. Many parents whose children had received input based on Conductive Education were strongly supportive of the approach, but had often faced serious challenges when requesting this provision for their child.

The inquiry heard clear evidence that "a child learns through play and physical interactions". (DCSF The National Strategies, Early Years Learning, Playing and Interaction – Good practice in the Early Years Foundation Stage, Crown Copyright 2009). There was a strong consensus, particularly among practitioners, that if there is a significant impairment through a condition such as a cerebral palsy, the child will require specialist intervention to develop their cognitive, physical, social and emotional skills in a joined up approach to enable the child to learn the skills that typically developing children learn spontaneously for play and physical interaction.

As children with cerebral palsies move on from early years provision into full-time education, the need for targeted, expert input within their school provision continues whether the child attends a mainstream or specialist provision. Practitioners considered it especially important at this stage that the impact of the multiple effects of cerebral palsies are fully identified and understood by all teachers and professionals who support the child, and that effective strategies are put in place to support learning and development in all areas. There was concern from parents that too much responsibility for supporting children with cerebral palsies in non-specialist settings was placed on under-trained teaching assistants and that school staff held misconceptions about what the child could be expected to achieve, for example with homework tasks.

Specifically, the inquiry heard the need for an integrated curriculum approach. A unified or 'blended' approach within the classroom setting, from either a specialist practitioner or a transdisciplinary

team, avoids the tendency to treat the child with a cerebral palsy as a raft of separate unrelated conditions, and means that a single programme can be put in place successfully to address all of the child's needs. A child need not be removed from the class for therapy, rather the child may have some focussed, intensive time to spend on one or more of their educational or personal goals if the practitioner judges it is the optimum time to do so. This is meaningful 'differentiation' for a child with a cerebral palsy which goes beyond the requirement to prepare and deliver a curriculum using different materials and equipment to meet each child's needs, but does, however, require a high level of knowledge and skill in meeting the needs of a child with a cerebral palsy.

The inquiry heard that many children with cerebral palsies will have significant difficulties with communication skills, which will impact on their ability to communicate both verbally and in writing. Practitioners stressed the vital importance of access to teaching and learning in the use of augmentative and alternative methods of communication including eye gaze and voice output technology. It was strongly felt that this provision should be implemented as early as possible in order to support the development of early language, conceptual skills and social skills. Unfortunately, too often, funding for this provision is delayed due to prolonged assessment procedures and restricted funding resources.

In summary, the inquiry heard that a combination of the lack of early identification of difficulty and appropriate intervention, educational practice and resources, leads to delayed, impaired or lost opportunities for early and continuing learning across the spectrum of development for many children with cerebral palsies. As a result, expectations of progress and achievement may be too low, typically leading to poor outcomes. Without early, specialised help, the child starts to experience failure in everyday activities. This leads to a 'learned behaviour' that can indeed manifest in an increasing perceived level of disability than the actual site of neurological damage.

However, the inquiry heard that when children with cerebral palsies had their needs correctly identified early and were able to access high quality specialist educational support, progress has been marked across all areas of development. Children with complex needs as a result of cerebral palsies have learnt how to move with control, communicate effectively, fully access the school curriculum, and take an active part in all their self-care needs. In short, the investment in early and ongoing specialist intervention has and will result in a young person and future adult who can take a full and active part in their own lives and make a meaningful contribution to society.

In summary, the key factors which restrict effective educational practice for children with cerebral palsies include:

- An over-emphasis on equipment-based intervention in the early years or school provision, rather than 'hands on' active sensory motor learning for children and aligned training for parents and practitioners.
- Insufficient levels of expertise in those responsible for assessing children with cerebral palsies at Statutory Assessment/EHCP stage and consequent poor identification and quantification of appropriate educational provision.
- Insufficient capacity in local services to provide adequate levels of therapy or specialist support and specialist equipment for children with cerebral palsies and their families.

- Lack of a ‘joined up’ teaching and intervention approach which recognises the inter-relationship and inter-dependency of the learning needs of children with cerebral palsies and the importance of active movement in the learning process. Instead, in the common model of support, each aspect of the child’s disability (movement, communication, functional skills etc) is ‘treated’ separately by respective therapists with a consequent lack of continuity, consistency and shared aims.
- Provision of a generic approach to teaching and learning within special needs nurseries or opportunity groups, rather than the specific and targeted input that the child with a cerebral palsy needs to address their individual needs.
- Lack of or inadequate initial training and CPD for teachers, advisory teachers and educational practitioners in special needs generally and cerebral palsies in particular. This is despite a strong move toward inclusion for children with special needs and disabilities into mainstream schools which will see many teachers required to teach and/or support children with cerebral palsies at some point in their career.
- Poor shared practice between specialist centres, voluntary organisations and charities, special schools and mainstream settings. Expertise which is present in specialist schools, centres, or voluntary organisations and charities is not being sufficiently utilised to inform, train and build knowledge and skills in nurseries and schools attended by children with cerebral palsies.

We would therefore recommend:

1. **Improved training for school based clinical and educational practitioners:** All clinical and educational practitioners (including SENCos) working with children with disordered development and/or cerebral palsies should receive training in the cerebral palsies at initial training and as continuing professional development.
2. **Improved access to specialist provision for families:** Access to specialist provision and expertise in the cerebral palsies from both statutory and third sector services is made available as an entitlement as soon as concerns are raised about a child’s development.
3. **A greater focus on active sensory motor learning:** Educational provision for children with cerebral palsies should recognise the fundamental importance of active sensory motor learning as the foundation for the development of functional skills. Educational programmes which integrate learning and therapy should be made available to children with sensory motor disorders.
4. **Recognition of the breadth of needs of children with cerebral palsies:** Practitioners in nurseries and schools should recognise the breadth and complexity of the learning needs of these children beyond the physical impairment and ensure that teaching methodology, differentiation, adaptation of curriculum and resources and any necessary environmental adaptations are appropriate to the child’s needs. This attention to detail should continue throughout the child’s school years and through transition to adult services.
5. **The development of ‘best practice’ guidelines for education professionals who work with children and young people with cerebral palsies.**

6. **Greater sharing of expertise between statutory and voluntary sectors, generalists and specialists:** Nursery and school settings working with children with cerebral palsies should be required to seek and share expertise with special schools, specialist charities and the independent and voluntary sector, working as equal partners in delivering high quality provision for children with cerebral palsies.
7. **Enhanced funding streams:** Protected funding should be made available at national level to ensure that early intensive intervention and ongoing high quality integrated educational provision is provided as a right to children with cerebral palsies.

3) Support and professional development for education and healthcare workers

The third theme within the terms of reference of the inquiry asked witnesses to consider potential improvements in the way that education and healthcare workers working with children with cerebral palsies could receive specialist training, development and support to help them in that work. It will already be apparent to the reader that the findings outlined earlier in this report focus substantially on the need for more specialist educators and therapists and for greater awareness of the condition amongst generalists (health visitors, GPs, SENCos, teachers and therapists).

This section will not repeat those arguments, which are outlined clearly enough in the sections above, but serves to bring together the recommended actions with respect to awareness, training and support, as follows:

1. **Improved awareness among generalists:** We have highlighted in sections 1 and 2 the need for:
 - a. Greater awareness of the cerebral palsies and other neurodevelopmental disorders among medical generalists (particularly GPs and health visitors)
 - b. Greatly improved understanding of the learning needs of children and young people with cerebral palsies among those working within schools (SENCos, teachers, LSAs and school-based therapists)
 - c. Improved understanding of the needs of children and young people with cerebral palsies and appropriate interventions among local authority commissioners and SEN manager.
 2. **Better workforce planning and training for practitioners:**
 - a. Evidence to the survey suggests that there should be an absolute increase in the number of therapists of all disciplines across the UK
 - b. In addition, we recommend that a greater number of them receive specialist training to help them assess very young children with neurodevelopmental disorders more quickly and accurately (particularly through the General Movements Assessment) and to provide more tailored therapy as those children develop
 - c. We also recommend the creation and widespread deployment of the “lead developmental therapist” concept, which will require training for senior therapists in transdisciplinary working and in the softer skills required in leading support for the family of a child with cerebral palsies
 - d. Finally, there is a need for NHS therapists to have a better understanding of therapy options that exist beyond those provided within the NHS and of the voluntary specialist services available locally.
 3. **Improved training for parents:**
 - a. Finally, and by no means least, we have outlined the clear importance of parents as educators and therapists to children with cerebral palsies. We recommend wholeheartedly that better training and support for parents and wider family members is central to the provision made available for children and young people with cerebral palsies.
-

4) Integrating health and educational support and ensuring a whole child approach

During the final evidence session, the inquiry was very pleased to hear evidence from senior officials from the Department for Education: Ann Gross (Director of Special Needs and Children's Services Strategy), Helen Stephenson (Director of Early Years and Childcare) and Phil Snell (Assistant Director, Special Educational Needs and Disability Unit). The inquiry heard more detail from the Department concerning the SEND reforms and the ways in which they were intended to respond to the specific needs of children with cerebral palsies.

The inquiry heard a strong and unanimous welcome of the intent behind the Government's reforms to special educational needs and disability (SEND) provision legislated through the Children and Families Act. The Act has the potential to significantly improve the lives of people with cerebral palsies. Key changes include the replacement Statements of Special Educational Needs with a single assessment process and an Education, Health and Care (EHC) Plan from 2014. The Act provides statutory protection comparable to those in Statements of Special Educational Needs for young people who are in education or training up to the age of 25 instead of ending at 16. Significantly there is also a requirement on health services and local authorities to jointly commission and plan services for children, young people and families. Local authorities now also must publish a 'local offer' to provide information about provision available to children with special educational needs in their area.

The introduction of EHC Plans was seen as a development of particular encouragement among respondents to the inquiry. If services for children and young people with cerebral palsies are to complement each other, then Plans should facilitate this by ensuring services are jointly commissioned and provision discussed in dialogue with parents. The stipulation that provision is set on the basis of

*"Parents/carers typically have to 'fight' to secure the best provision for their children; this means that those parents who are most vulnerable and often in most need, find it hardest to secure help".
John de Bono QC*

the outcomes they are expected to achieve for the child or young person, agreed between professionals and parents, has been very much welcomed. There is a belief that if this is followed through it should create the promised cultural shift that leads assessments for special educational provision to be based on a continuing assessment of a child's needs and expected progress, rather than simply a fight over short-term solutions for long-term issues.

However, despite the best intentions of the reforms, parents and practitioners told the inquiry that many years of battling with education and health authorities over support for children with cerebral palsies has left them doubtful of whether the reforms will make a difference. The negativity about the potential of the reforms is the legacy of an adversarial SEND system, where the parents and practitioners involved have been left battle-weary and sceptical that change may be achieved. There remains a fear that while the reforms could improve the situation for children and young people with cerebral palsies slightly, it will not address the widespread lack of understanding of the needs of children and young people with cerebral palsies that directly contributes to a systemic antagonism where parents have to fight too hard to prove what support their children need.

"The Government's ambitions for disabled children and those with SEN, including those with cerebral palsies, are really the same as for all other children. We want to see them achieving well in their early years, in school, in college. To find employment where that's possible, and to be able to lead very full lives". Ann Gross, Director of Special Needs and Children's Services Strategy, Department for Education

*“The EHC plan system will be more of an administrative revolution for local authorities than a revolution for the provision of services”.
Nageena Khalique, Head of Public Law, No.5 Chambers.*

Solicitors and barristers with extensive experience of representing children with cerebral palsies and their families provided important perspectives on the new Act and the SEND provisions within it. There was a strong sense that the reforms under the Act fell short of creating a truly integrated approach to education, health and social care. In particular, they noted the shortcoming that EHC plans only require Local Authorities to identify and record healthcare needs

that affect the child’s ability to learn rather than fully reflecting his or her healthcare needs. In addition, it was noted that the Code of Practice requirement that nursery schools use their “best endeavours” to ensure that a child with SEN gets the support they need allowed a unnecessary latitude that could result in material shortfalls in the quality and quantity of provision.

There was also the feeling that an opportunity was missed to significantly improve early intervention services for children with complex needs, such as a cerebral palsy. In particular the SEND Code of Practice, the statutory guidance explaining how the reforms should be implemented, is supposed to cover the age range 0-5, but it was felt there is insufficient reference made to the 0-2 age range – the age range crucial for identifying children with cerebral at an early stage. The Code does not provide adequate guidance to cover support for children in the 0-2 age range at all, as prior to the 2 year check the responsibilities of health services to identify needs are not clear. Neither is it clear how local authorities are involved in their assessment of their needs at this stage. In addition, health services should be encouraged to offer direction to parents to find emotional, social and educational support for children.

“Children with cerebral palsies are inevitably a genuine special case with complex and often wide ranging disabilities and needs necessitating a truly integrated approach to their care to ensure their health and well-being needs are met and to maximise their potential”. Paula Barnes (Partner, Moore Blatch)

Health services, parents and early years providers need to be made far more aware of how children with cerebral palsies can be supported; every day that a child misses out on specialist intervention diminishes their chance of significant improvements to their lives and increases the cost of long-term support to the State.

During the final session of the inquiry, officials from the Department for Education stated their desire to engage with Action Cerebral Palsy and other specialist organisations to build a common understanding of the issues and to ensure that the incoming SEND reforms work as well as possible for children with cerebral palsies. That engagement is welcomed and Action Cerebral Palsy and its stakeholders look forward to that dialogue in the hope that outcomes for children with cerebral palsies and their families can be materially improved. This is why, first and foremost, we would recommend:

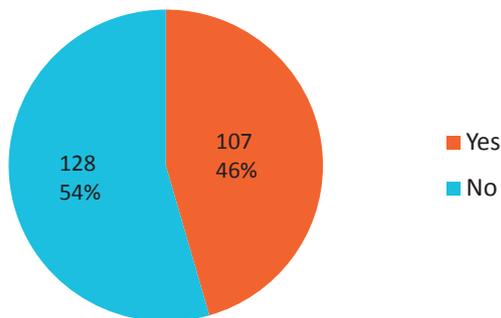
The formation of a multi-disciplinary taskforce.

The taskforce will comprise representatives from the Department for Education and Department of Health, local government, NHS and NICE, schools and voluntary sector organisations to take forward the findings of this report, to develop a national strategy for children and young people with cerebral palsies and to ensure its implementation.

Appendix – Key Family Survey Results

1) How old is Your Child			2) Age Child Diagnosed with cerebral palsies		
AGE	NUMBER	%	AGE	NUMBER	%
LESS THAN 3 YEARS OLD	18	8	0-5 MONTHS	57	24
NURSERY AGE (3 OR 4)	58	24	6-11 MONTHS	65	27
PRIMARY SCHOOL AGE (5-11)	100	42	12-17 MONTHS	46	19
SECONDARY SCHOOL AGE (11-18)	47	20	18-23 MONTHS	32	13
19 OR OLDER	15	6	24-29 MONTHS	16	7
TOTAL RESPONDING	238	100	30-35 MONTHS	7	3
			36 MONTHS OR OLDER	16	7
			TOTAL RESPONDING	238	100

3) Did you feel the process of diagnosis worked as it should?



4) How easy did you find it to access specialist support and advice?

	DIFFICULT	★	★★	★★★	★★★★	EASY
Prior to and during the process of diagnosis	83. 35%	54. 23%	41. 17%	26. 11%	33. 14%	
Immediately after diagnosis	56. 24%	54. 23%	48. 20%	37. 16%	40. 17%	

5) What is the level of complexity of your child's needs?

	LESS COMPLEX	★	★★	★★★	★★★★	MORE COMPLEX
	13. 5%	31. 13%	65. 27%	71. 30%	59. 25%	

6) Which of the following NHS services did you and your child access during their early years (0-3 years)

SERVICE	NUMBER	%
PHYSIOTHERAPIST	223	94
HEALTH VISITOR	190	81
OCCUPATIONAL THERAPIST	179	76
SPEECH AND LANGUAGE THERAPIST	167	71
NHS CHILDREN'S CENTRE	92	39
SPECIAL NEEDS HEALTH VISITOR	40	17
OTHER	57	24

7) NHS Support in Early Years

★ ★★ ★★★ ★★★★ ★★★★★

How would you rate the knowledge and expertise of the NHS professionals who worked with your child during their early years?

22. 9% 40. 17% 83. 35% 65. 27% 29. 12%

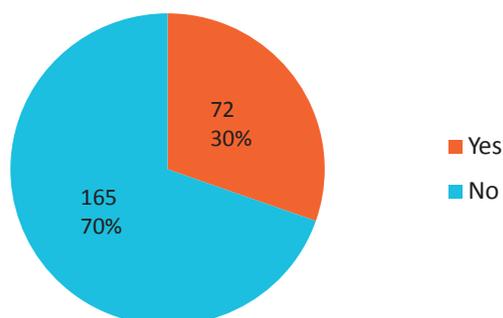
How would you rate the quality of NHS support that you and your child received in their early years (0-3 years of age)?

34. 14% 54. 23% 74. 31% 61. 26% 19. 8%

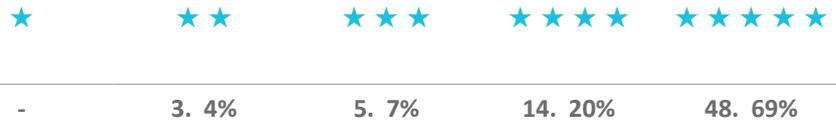
How would you rate the availability and intensity of NHS support during your child's early years (0-3 years of age)?

57. 24% 54. 23% 74. 31% 36. 15% 15. 6%

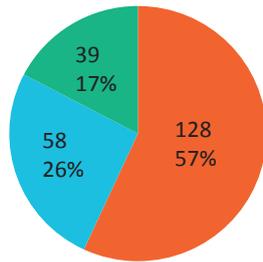
8) Has your child attended a specialist centre for children with cerebral palsies (and related conditions) during their early years?



9) How would you rate the provision that your child received at that specialist centre?



10) What kind of educational (nursery or school) setting does/did your child attend?



- Mainstream nursery/school
- Specialist nursery/school for children with CP
- Other special nursery/school

11) What therapeutic input does your child receive?

	NUMBER	%
PHYSIOTHERAPY	211	92
OCCUPATIONAL THERAPY	182	79
SPEECH AND LANGUAGE THERAPY	139	60
CONDUCTIVE EDUCATION	65	28
OTHER	33	14

12) How/where does your child receive the majority of their therapeutic input?

AGE	NUMBER	%
WITHIN THEIR NURSERY/SCHOOL, INTEGRATED INTO THE CURRICULUM	74	33
OUTSIDE NURSERY/SCHOOL FROM NHS THERAPISTS	66	29
WITHIN THEIR NURSERY/SCHOOL IN SESSIONS OUTSIDE THE CLASSROOM	42	19
OUTSIDE NURSERY/SCHOOL FROM PRIVATE THERAPISTS	24	11
OUTSIDE NURSERY/SCHOOL FROM A SPECIALIST CENTRE	18	8

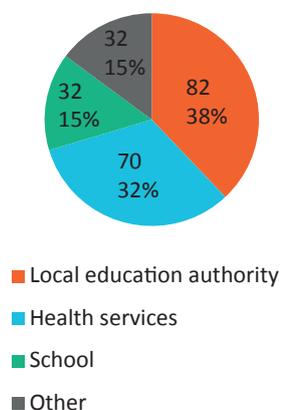


13) How would you rate the quality of the therapeutic input that your child receives?

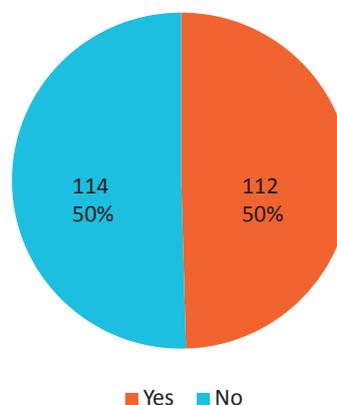


	★ DIFFICULT	★★	★★★	★★★★	★★★★★ EASY
14) How easy has it been for you to secure appropriate educational and therapy support for your child?	50. 22%	49. 22%	65. 29%	40. 18%	20. 9%

15) What has been the biggest obstacle to getting the appropriate education and therapy support for your child?



16) Do you feel that education and health services have worked together to support your child?



17) How did you find the specialist centre for children with cerebral palsies (and related conditions) that your child attends?

	NUMBER	%
WORD OF MOUTH	48	53
INTERNET RESEARCH	25	27
NHS REFERRAL	14	15
SCOPE	13	14
PORTAGE	10	11
LOCAL AUTHORITY CHILDREN'S SERVICES REFERRAL	6	7
LOCAL EDUCATION AUTHORITY REFERRAL	2	2
OTHER	9	10

Action Cerebral Palsy warmly acknowledges the generous contributions of the parents, practitioners and other experts who have given their time and expertise to this inquiry:

Jabeen Akhtar, parent

Tom Reddy, parent

Emma Holding, parent

Paul Kelly, parent

James Melville-Ross, parent

Rachel Taplin, parent

Hanaagh Smith, parent

Philip Lea, parent

Lee Gough, Chief Executive, Megan Baker House

Eniko Kocsis, Interim Service Manager, The Rainbow Centre

Lara Bull, Business Support manager, The Rainbow Centre

Steven Lane, Chief Executive, Dame Vera Lynn Trust

Karen Hague, MBE, Co-Founder of Paces Sheffield

Amanda Richardson, Chief Executive, The PACE Centre

Dr Melanie Brown, Chief Executive, The National Institute of Conductive Education

Lesley Cannings, retired Physiotherapist, Ingfield Manor School

Laurel Allen, Paediatric Speech and Language Therapist, The PACE Centre

Lindsay Hardy, Paediatric Speech and Language Therapist, The PACE Centre

Christine Barber, Director of Therapy of The Bobath Centre for Children with Cerebral Palsy.

Dr Christopher Verity, Consultant Paediatric Neurologist, Addenbrooke's Hospital

Betty Hutchon, Head of Paediatric Occupational Therapy, Royal Free Hospital

Professor Narender Ramnani, Professor of Neuroscience, Royal Holloway, University of London

Dr Karen Horridge, Paediatrician (Disability), Sunderland and Chair of the British Academy of Childhood Disability

Professor Rosemary Varley, Division of Psychology and Language Sciences, University College London

Paula Barnes, Partner and Head of Community Care, Moore Blatch Solicitors

John de Bono QC, Sergeants' Inn Chambers

Nageena Khalique, Head of Public Law, No5 Chambers

Ann Gross, Director of Special Needs and Children's Services Strategy, Department for Education

Helen Stephenson, Director of Early Years and Childcare, Department for Education

Phil Snell, Assistant Director, Special Educational Needs and Disability Unit, Department for Education

...and to the 238 parents who responded to the family survey and those who provided written evidence that formed part of this inquiry.
