



VARIATIONS IN CARE

**AN ANALYSIS OF PROVISION OF
PATHWAYS OF CARE FOR INFANTS
AND CHILDREN WITH CEREBRAL
PALSY ACROSS THE UNITED KINGDOM**

Two-year review report

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Action Cerebral Palsy was formed in 2013 and is now an active, independent national campaigning charity that seeks to represent the cerebral palsy community, as a voice for this under-represented group.

Our vision is that every child and young person in the UK with cerebral palsy can access, from birth, the best possible intervention, care, education and support to meet their complex and changing needs.

I am delighted to present Action Cerebral Palsy's second report analysing the provision of pathways of care for infants and children with cerebral palsy.

Following our 2015 Parliamentary Inquiry; 2016 inaugural report on cerebral palsy provision across the UK; and our Winston Churchill Memorial Trust report last year on global best practice, our second report details that little progress has been made.

It is clear from the responses to the 2018 Freedom of Information request that many families affected by cerebral palsy continue to suffer from a postcode lottery of arbitrary and incoherent care plans. Generic services for physically disabled children are still present, rather than properly individually tailored programmes that can support the complex and inter-related health and developmental needs of children with cerebral palsy.

The current lack of clear, nationally implemented pathways of care for infants and children with or at risk of cerebral palsy, or indeed any neuro developmental condition, highlights the fragmented state of services across the country and is unacceptable. This situation requires urgent attention.

Action Cerebral Palsy has three clear asks of decision-makers to improve the lives of children with cerebral palsy and their families across the United Kingdom:

- ① **IDENTIFY** Create a national Cerebral Palsy Register to improve the collection of data about the incidence, diagnosis, medical history, developmental needs and outcomes of children with cerebral palsy. A robust and consistent data collection system will improve service planning, support the implementation of fit for purpose medical, care and educational pathways and facilitate research into the condition;
- ① **INTERVENE** Equip GPs, health practitioners such as Health Visitors, clinicians, early years practitioners and teachers with specific knowledge on cerebral palsy, to ensure that those on the front line have the knowledge they require to intervene and/or refer effectively;
- ① **IMPACT** Implement best practice pathways of care throughout the United Kingdom and champion earlier detection, diagnosis and intervention to help achieve maximum independence for children with cerebral palsy.

If you would like to help us by meeting us, sharing your expertise or donating, please email: amanda.richardson@actioncp.org

With best wishes,



Amanda Richardson MBE
Chief Executive, Action Cerebral Palsy



Amanda Richardson MBE has over thirty years' experience as an educator of and advocate for children with cerebral palsy in both mainstream and special school settings.

EXECUTIVE SUMMARY

- Cerebral palsy is an umbrella term for a group of motor disorders caused by damage to the immature or developing brain which may occur before or after the birth of a child. The impact of cerebral palsy can range from mild to severe and it can affect all aspects of childhood development.
- With a UK incidence of about 1 in 400 births, or 1,800 children per year, these conditions are the most common physical disabilities in childhood, and can affect those from all social backgrounds, genders and ethnic groups.
- A Freedom of Information (FOI) study was commissioned by Action Cerebral Palsy in 2018 to consider the provision of cerebral palsy services across England, and to review how the state of provision has developed since an initial FOI conducted in 2016 and subsequent [report published in 2017](#).
- The focus of ACP's study was on services provided by NHS community and foundation trusts and local authorities.
- As was the case with our 2016 FOI survey, a large proportion of NHS trusts and local authorities did not hold information centrally (including basic information such as the number of Health Visitors employed by the trust or the number of children diagnosed with cerebral palsy).
- A high proportion of trusts and local authorities appear not be using measures available to them to monitor need, provision and services.
- Despite low information capture rates, there appears to be a slight improvement in the number of specialists provided by trusts and the training that is given to non-specialist health professionals.
- It is clear from the evidence provided that Scotland demonstrates a better overall provision of specialist care than the other UK nations, and we would attribute this to the presence of a Cerebral Palsy Register in place there, with the ability to map provision and tailor services accordingly.
- Based on the variance in answers provided, there appears to be highly variable provision across services in England – a postcode lottery. **Only 22 NHS Trusts out of the 169 who responded were able to provide a timetable for referral for children with suspected cerebral palsy and only 10% were able to say that they have a formal care pathway specifically for children and young people with cerebral palsy. Worryingly, only 13 NHS Trusts were able to respond saying that they had adopted the NICE Guidelines on the Assessment and Management of Cerebral Palsy in Under 25s (January 2017).**
- **Progress has been too slow since the publication of the NICE Guidelines and services are not responding quickly enough to clear research evidence on the vital importance of early intervention for neuro developmental conditions such as cerebral palsy. There is a need to act now to ensure that *all* children at risk of cerebral palsy or neuro developmental delay across the United Kingdom have access to the very best care pathways and health and educational intervention to improve their life chances and wellbeing.**

Action Cerebral Palsy's second report into provision for children and young people with cerebral palsy across the United Kingdom comes shortly after its Chief Executive, Amanda Richardson MBE, was awarded a Winston Churchill Memorial Trust Fellowship Award to explore global best practice in cerebral palsy provision. Amanda, accompanied by the charity's Director of Communication and Policy, Caroline O'Shea, visited Australia and, subsequently, compiled a sector-leading report comparing the Australian model, as a global leader, with provision in the United Kingdom, which was launched in the Speaker's Apartments in early 2019.

Our research showed that the introduction of an Australian Cerebral Palsy Register has been integral to better and earlier provision, making it infinitely easier to map the number of children and young people diagnosed, what symptoms they have, and what their health outcomes are. The introduction of the Register has enabled improvements including the monitoring of progress of children with, or at risk of, cerebral palsy and extra resources being allocated to research the causes and prevention of the condition. This, in turn, has led to the implementation of best practice which has resulted in the rate of cerebral palsy amongst new-born children starting to fall, as evidenced in the Report of the Australian Cerebral Palsy Register 2018.

In the United Kingdom, Northern Ireland has an established Cerebral Palsy Register, administered by Queen's University Belfast and there is an emerging register in Powys, Wales. The Cerebral Palsy Integrated Pathway (CPIP), run by paediatric physiotherapists, collects information about orthopaedic procedures. However, across the UK, and in England in particular, knowledge is still so patchy and variable that it is currently extremely difficult for healthcare trusts to track the number of children and young people with the condition and therefore to provide the relevant resources. For example, most of the NHS trusts who did provide numbers of children and young people with cerebral palsy were only able to make an estimation based on the number of children logged in hospital visits.



RECOMMENDATIONS

Since the first FOI investigation and its resulting report was conducted in 2016, Action Cerebral Palsy has been committed to raising awareness amongst healthcare leaders, education providers and Government of the importance in quickly identifying children who might have cerebral palsy and intervening during the critical first two years to give them access to the therapies they need. Our *Identify, Intervene and Impact* campaign makes the following recommendations:

- Early identification, assessment and intervention for all children with, or at risk of, cerebral palsy.
- Nationally-implemented integrated education and health pathways for children with, or at risk of, cerebral palsy to ensure best practice, early intervention and a holistic approach.
- Regional trans-disciplinary centres of excellence for infants and children with, or at risk of, neurodevelopmental conditions such as cerebral palsy.
- A national register of children with cerebral palsy to aid best practice pathways, provision planning and research.
- The engagement of specialist educational support to help children with cerebral palsy develop their potential.
- Improved training and professional development of education and healthcare professionals to increase their awareness and assist them in detecting the early signs of cerebral palsy in babies and children.



🎯 VARIATIONS IN CARE: AN UPDATED REVIEW OF CEREBRAL PALSY PROVISION

INTRODUCTION

Following our 2015 Parliamentary Inquiry; 2016 inaugural report on cerebral palsy provision across the UK; and our Winston Churchill Memorial Trust report last year on global best practice, our second report details that little progress has been made.

It is clear from the responses to the 2018 Freedom of Information request that many families affected by cerebral palsy continue to suffer from a postcode lottery of arbitrary and incoherent care plans. Generic services for physically disabled children are still present, rather than properly tailored programmes that can support the complex and inter-related health and developmental needs of children with cerebral palsy. It is disappointing that little progress has been made nationally since the 2015 Parliamentary Inquiry into how the lives of the estimated 30,000 children with cerebral palsy could be improved.

This level of variation is nothing less than a national disgrace, and it is simply unacceptable that services are letting down families when they are most at need of support. Scotland's responses and support for those affected by cerebral palsy is an exemplar of how striving towards good practice is possible, and that genuine progress can be made.

This report outlines the findings of Action Cerebral Palsy's 2018 Freedom of Information (FOI) study into the provision of cerebral palsy services across England carried out between April and December 2018. It focuses on services provided by local authorities and provided by NHS Trusts and follows up on an FOI survey carried out in 2016.

Since this time, and spurred on by the results of the investigation, Action Cerebral Palsy has carried out a high-level information and awareness campaign, 'Identify, Intervene, Impact', seeking to raise awareness at the highest level of Government, education and health services as to the importance of monitoring the number of children likely to have cerebral palsy and of having a clear pathway of care to ensure that these children can benefit at the earliest opportunity from the full range of therapies available.

The survey found that, whilst there were some slight improvements in provision, levels of care were highly variable across England and there is little evidence of trusts and local authorities using the tools available to them to track need and monitor provision of services for children and young people with cerebral palsy.

Some NHS Trust shared detailed plans in place to provide a cross-section of services for children with cerebral palsy. Others stated that they had no plan or expressed complete unawareness of any provision for children with the condition. A small minority of trusts responded that they were aware of the need for a distinctive plan, but that these were still in the process of being implemented.

The report detailed below analyses our findings from this round of FOIs and looks at how service provision, reporting and coordination has developed in the last two years. The report outlines the questions put to each trust and provides an overview as to their responses in comparison with the 2016 report. It highlights those NHS trusts and local authorities which have demonstrated best practice in terms of cerebral palsy care and examines examples of confusing or inefficient services managed, as well as identifying critical areas for improvement.

BACKGROUND

As in 2016, the questions included in the FOI request were based on the recommendations from the 2014 Parliamentary Inquiry which highlighted that:

- Early identification is critical because, as a result of neuroplasticity, intervention is most effective in the first 24 months. However, there are barriers due to a lack of specialist support, variable routes to diagnosis and a lack of knowledge at health visitor and GP level.
- Provision of specialist education is patchy and is more likely to focus on physical, rather than developmental, challenges. Health professionals need to have the expertise to advise families on how to access relevant resources and generalist providers need to have the skills to provide basic services for children and young people with cerebral palsy.
- Professional development needs to be improved for education and healthcare professionals.
- Educational and health support should be integrated to best meet the particular needs of the individual child, as opposed to the current generic measures available.

Following this, NICE guidelines on [Cerebral Palsy in under 25s: Assessment and Management](#) were released in January 2017. These recommendations included:

- Recognition of the risk factors for cerebral palsy.
- The provision of an enhanced clinical and developmental follow up programme by a multi-disciplinary team for children up to 2 years of age at risk of cerebral palsy.
- Recognition of abnormalities of tone and/or motor development which may indicate signs of cerebral palsy.
- Referral of infants who have abnormal motor features associated with cerebral palsy for urgent assessment.
- Referral of all children with suspected cerebral palsy to a child development service for an urgent multidisciplinary assessment in order to facilitate early diagnosis and intervention.
- Referral of all children with delayed motor milestones to a child development service for further assessment.
- Ensuring effective communication and integration between health and social care providers.

The questions contained in this FOI survey focused upon information gathering, care pathways, and specialist provision, both in therapy and education and training. These aimed to discover how provision and coordination had developed in the two years since the 2016 survey and whether NHS trusts and local authorities were utilising the tools available to them to manage provision effectively.

KEY FINDINGS

- The total number of English NHS trusts contacted in 2018 was 189, 169 provided a response and 60 did not provide any information at all. The total number of trusts including Northern Ireland, Scotland and Wales is 215, and 186 responded in total. The total number of Local Authorities approached is 151 and the total responses were 147.
- The majority of Trusts and Local Authorities could not easily provide basic information about the number of children diagnosed with cerebral palsy, access to general or specialist healthcare professionals or whether a care pathway was available to them. **The response was particularly poor from local authorities of whom only six could tell us how many children with cerebral palsy lived in the local area.** Many of the trusts who were able to give an answer, mainly large hospital trusts, told us that this information was only available because it had been recorded during visits by the children to hospital. The results suggest that trusts and local authorities do not have a systematic way of recording and centrally collecting the numbers of children with cerebral palsy.
- **The majority of NHS trusts still do not have a formal care pathway for children with cerebral palsy.** Many use a catch-all pathway for children with physical disabilities. Similarly, responses suggest that care plans revolve around access to physiotherapy rather than a more rounded approach drawing on all therapies.
- There is a **slight improvement in access to trained education and healthcare professionals** and, similarly, a **slight improvement in training made available to GPs and Health Visitors.**
- **Trusts and local authorities are not taking up opportunities to ensure quick identification, integrated care and a managed pathway,** which would lead to better monitoring and allocation of funding to the right services.

Early identification, assessment, and intervention for children with cerebral palsy

The 2014 Parliamentary Inquiry found that more needed to be done to support children and young people with cerebral palsy, particularly in the first 24 months of a child's life when interventions are at their most effective, but sadly also often absent.

The 2018 Report finds that, contrary to the NICE recommendations, few trusts were able to evidence an urgent approach to identification, assessment and intervention. **Only 22 NHS trusts were able to provide a timetable for referral to treatment for children with suspected cerebral palsy,** and 13 of these cited the standard 18-week referral to treatment timeline. Nine trusts gave a specific timeline, with the average being 10 weeks and the shortest being 1-2 weeks. The fact that so very few trusts have a timeline in place indicates that they may not be aware of the urgency of diagnosing cerebral palsy in young children and the positive impact of giving them early access to appropriate therapies. The number of trusts able to give a timeline for referral to treatment was very similar to the number that gave one in 2016 (21) indicating that very little has happened within the NHS to increase the understanding of the urgency of referring patients and demonstrating that there is a need to set guidelines and standards to support this.

Engaging specialist educational support in helping children with cerebral palsy to develop their potential

The 2014 Parliamentary Inquiry found that, although there were cases of excellent educational provision for children with cerebral palsy, outcomes were varied and many children were failed by a system that is too generic in its approach. Specifically, provision for children too often focuses on physical challenges rather than developmental challenges.

In 2018 our FOI survey found that trusts and local authorities were quick to point to provision of physical therapies – especially physiotherapy – rather than all the developmental therapies. There was a slight improvement in the average number of paediatric speech and language therapists employed by trusts compared to the 2016 report (an average of 17 compared to 14.5). Very few trusts (2) were able to provide the number of children referred to developmental clinics in their area, suggesting that these clinics simply do not exist, or that there is no overview to assess need and provision. Similarly, under 5% of local authorities were able to give a figure for the number of children with cerebral palsy listed on their Education, Health and Care plan - a worrying sign four years after these plans were created.

In terms of access to local specialist schools, only 18 local authorities were able to provide this information, a marked decrease from the 39 local authorities who did so in 2016. 30 local authorities did highlight specialist education provision outside but close to their locality but, although a few were able to provide a long list of specialist centres, the majority only named one school, indicating that children and their families continue to face daily inconvenience to access the education that they need.

Improve professional development for education and healthcare

The 2014 Parliamentary Inquiry found that awareness of cerebral palsy among medical generalists was limited and in need of improvement. It was also noted that improved training for, and an increase in number of, therapists trained to work with children and young people with cerebral palsy was required.

Of all the questions asked of NHS trusts and local authorities, this topic generated the greatest number of responses and those responses suggest that there is a degree of improvement in staff development and training, although training for professionals of all types varies greatly with little uniform practice in place.

24 local authorities were able to provide details of the training and advice provided to Health Visitors and school nurses on identifying and referring children suspected of having cerebral palsy compared to only 9 in 2016. Whilst this is low, it does suggest a slight improvement in training provision compared to figures from 2016. However, teachers themselves are rarely trained in cerebral palsy specifically.

31% of NHS trusts were able to provide information on different levels of training ranging from ad hoc specialist training, ongoing staff development and access to specialists. However, 16 trusts reported that no training is given to healthcare professionals.

Integrating health and educational support and ensuring a whole child approach

The 2014 Parliamentary Inquiry expressed hope that the changes introduced by the Children and Families Act and the SEND reforms would be effective in integrating educational and healthcare support, but had concerns that education and health services were too disparate, with limited exchange or referral routes between them.

The 2016 FOI investigation found that integration of services was low across the country, with disparate bodies operating across geographies and few identifiable mechanisms for exchange between them.

In 2018, under 5% of local authorities were able to give a figure for the number of children with cerebral palsy listed on their Education, Health and Care plan, a worrying sign four years after these plans were created, and a suggestion that local authorities and health trusts have not taken the steps available to them to integrate service provision most effectively. The number of local authorities able to supply this information was the same as that in 2016, but the 2018 survey found an increase in the average number of EHCPs from 4 to 46. This suggests that adoption of the EHCPs may have increased, but has not been accurately reported.

A specific care pathway, as outlined in the 2017 NICE guidelines would boost opportunities for communication and integration between trusts and local authorities. However, our 2018 survey found that **only 10% of NHS trusts were able to say that they have a formal care pathway specifically for children and young people with cerebral palsy** and only 14 out of 408 local authorities (3.4%) were able to give details of a care pathway for children in their area. Although integration was not questioned directly as part of the survey, there was some evidence in the responses of trusts and local authorities working together in delivering integrated education, health and social care plans for children with cerebral palsy. For example, Kensington and Chelsea Council has recently introduced a new process of alert, together with local trusts, to coordinate provision of care. Redbridge Council highlighted liaison with North East London Foundation Trusts in providing care for children through its Community Medical Paediatrics Service.

Adhering to the NICE 2017 guidelines

Only 13 NHS trusts were able to respond saying that they had adopted the NICE guidelines as part of their care pathway, with three others detailing a formal pathway of diagnosis and care for children and young people with cerebral palsy, three more being able to inform us that they were in the process of creating one and another trust providing a detailed informal pathway. Altogether, this is 10% of the total number of NHS trusts, a slight reduction from the 14% of trusts following a specific pathway in the 2016 survey. 3.4% of local authorities gave us evidence of a care pathway with only two of these referencing NICE guidelines.

Access to specialist communications support

The NICE guidelines highlight the importance of access to specialist training in speech and language and training of teachers to aid pupils with communication.

Only 45 NHS trusts gave a figure for the number of paediatric speech and language therapists compared to 119 in 2016, and figures ranged from 0 (five trusts reported this) to 68 Whole Time Equivalent (Sussex Community NHS Foundation Trust). The average number employed was 17 (slightly higher than the 14.5 reported in 2016).

Local authorities told us that training, when offered, was directed at school nurses rather than the teachers themselves, indicating that there was a lack of understanding of the vital role that early years practitioners and teachers can play in meeting the inter-related developmental needs of children with cerebral palsy. There is a need for local authorities to have more awareness about how they can support healthcare providers in the application of the care pathway.

Recognition of the importance of early intervention

As reported above, our survey found that few trusts were able to evidence an urgent approach to identification, assessment and intervention. Only 22 NHS trusts were able to give us a timetable for referral to treatment for children with suspected cerebral palsy and 13 of these cited the standard 18-week RTT timeline. Nine trusts gave a specific timeline, with the average being 10 weeks and the shortest being 1-2 weeks. The fact that so very few trusts have a timeline in place indicates that trusts are simply not aware of the urgency of diagnosing cerebral palsy and the impact of giving them early access to the appropriate therapies.

Information for parents and carers

Similarly, it was apparent from the local authority response that more can be done to provide information to parents and carers about support for children with cerebral palsy with **only 3 local authorities out of a total of 408 being able to say that information about services specifically catering for cerebral palsy were made available through their Local Offer**. This is a marked decrease from the 2016 survey in which 46 local authorities responded with details of cerebral palsy support in their Local Offer.

Effective communication and integration between health and social care providers

As described above, there was a very low response from local authorities for the number of children with Education, Health and Care Plans, but it does appear that the average number of children with EHCPs per local authority has increased. There was some anecdotal evidence contained in the responses which suggests coordination of communication, but it is clear that trusts and local authorities need more impetus to work together and ensure that services are provided in a coordinated manner in order to comply with the NICE guidelines.

CONCLUSIONS

It is clear from the responses of the 2018 FOI request audit that many families affected by cerebral palsy continue to suffer from a postcode lottery of scattered and incoherent care plans that point them towards generic services for physically disabled children, rather than properly-tailored programmes that can support the complex and inter-related health and developmental needs of children with cerebral palsy.

As in the 2016 Report, failure to provide even basic information as to the number of children and young people diagnosed or the acknowledgement of the need for specific care pathways would indicate that trusts and local authorities need to have more awareness of children with cerebral palsy. The disparity in provision and approach across England is an indicator that trusts and local authorities are not aware of the importance of a distinct care pathway, joined up provision of education and health care and specialist training in supporting young people with cerebral palsy.

Although there are some improvements in terms of training and specialist provision since the 2016 report, there is still a worryingly long way to go four years on from the inquiry in terms of coordinated care and there are signs that both trusts and local services are failing to implement the NICE guidelines and Education, Health and Care Plans as frameworks for implementing best practice.

These trends illustrate the fractured nature of cerebral palsy care in England and that many children do not receive the quality of care that they require. In particular, the lack of urgency given to prioritising early diagnosis and intervention since the 2016 Report may suggest that the root problems that arise from cerebral palsy are exacerbated as children grow up without the proper therapeutic intervention, education and support they require.

Progress has been too slow since the publication of the NICE guidelines, and provision is not responding to clear research evidence and the vital importance of early intervention for neurodevelopmental conditions. This situation is unacceptable and action must be taken now. There remains a need for nationally agreed protocols for identification, assessment, diagnosis and monitoring. The need for improved levels of intervention has only become more necessary since the findings of the 2016 Report. Early intervention and intensive therapy can mitigate the impact of cerebral palsy and training for practitioners in the risk factors and signs of cerebral palsy must be improved so that intervention can be started as early as possible in order to achieve optimal developmental outcomes.

🎯 OVERVIEW OF FINDINGS

Below is an outline of the responses received to every question posed by this inquiry. It is notable that there is a paucity of information across local authorities and NHS Trusts with many organisations failing to provide details of their offer for children with cerebral palsy and their families.

It is apparent that the majority of NHS trusts and local authorities are failing to use the tools available to them – a dedicated care pathway, Education, Health and Care Plans and set timelines for referral to treatment – to monitor how services are provided to children and young people with cerebral palsy. This suggests that NHS trusts and local authorities do not have a clear idea of the need for services or what funding should be allocated towards them.



1. NUMBER OF CHILDREN AND YOUNG PEOPLE DIAGNOSED WITH CEREBRAL PALSY IN THE PAST FIVE YEARS

42 NHS trusts were able to access and send us data on the number of children and young people diagnosed with cerebral palsy in their area. The average number of children diagnosed was 173, compared to 219 in 2018. South Tyneside NHS Foundation Trust has 17 and Airedale NHS Foundation Trust has 24, whereas Alder Hey Children’s NHS Foundation Trust diagnosed 679 and Birmingham Children’s Hospital NHS Foundation Trust recorded 457 – higher figures which should be expected from specialist children’s hospitals.

Overall, 22% of trusts were able to provide an answer, a very low percentage for what we believe to be a simple question. 80 trusts stated that they do not, or are unable to, collect data on the number of children and young people diagnosed with cerebral palsy in the past five years.

Many of the trusts who did answer put caveats on their response as they gather information from hospital visits rather than from any standard recording procedure taking place around the time or shortly after the child’s birth. If such a procedure was put in place for Health Visitors or community midwives, it would be possible to have a far more accurate picture. The fact that 42% of trusts told us they were unable to collect the data is a worrying sign. **Even 5 years after the 2014 Parliamentary Inquiry, the fact that trusts have not made a concerted effort to collect this very basic information about children with cerebral palsy in their area is a cause of great concern.**

This table outlines the Trusts that record the highest number of children diagnosed:

NHS Trusts	Number of children diagnosed
Alder Hey Children’s NHS Foundation Trust	679
University Hospital Birmingham NHS Foundation Trust	668
Barts Health NHS Trust	518
Birmingham Children’s Hospital NHS Foundation Trust	457
King’s College Hospital NHS Foundation Trust	493
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	419

2. WHAT IS THE CARE PATHWAY FOR CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY IN YOUR TRUST/HEALTH BOARD?

Three trusts including St. Georges Hospital, the Royal Cornwall and Mid Cheshire, informed us that they had a formal care pathway. Thirteen further trusts responded saying that they are following NICE guidelines, or were developing their own pathways to adhere to the NICE guidelines and a further three did not refer to the NICE guidelines, but said that they were in the process of creating a specific pathway for children and young people with cerebral palsy. Hull and East Yorkshire does not yet have a formal pathway, but has a number of services working together as an informal pathway and have carried out work to identify where services can work together in a more integrated way to provide better and more coordinated access. In total, this accounts for 10% of the total number of trusts - a reduction in the 2016 response of 14%.

37 responding trusts said that there was no specific formal pathway. Others set out a general pathway for children with physical disabilities and two trusts were able to provide a detailed informal pathway referring them to a specialist cerebral palsy centre. Many answers indicated that there was not a specific care pathway for children and young people with cerebral palsy but would be integrated into a wider, multi-disciplinary pathway where cerebral palsy would be detected.

Some acute trusts pointed to community trusts for more information on care pathways and one, Great Western Hospitals NHS Foundation Trust, referred us to Swindon County Council. 26 trusts replied saying they did not know whether a pathway existed or not.

3. IS THERE A SPECIFIC TIMESCALE SET OUT IN YOUR CARE PATHWAY FOR REFERRAL TO A CHILD DEVELOPMENT SERVICE FOR DIAGNOSIS OF CEREBRAL PALSY FROM THE POINT WHEN SYMPTOMS ARE INITIALLY IDENTIFIED?

22 trusts responded to this question with a specific answer. Of these, 13 pointed to the standard referral to treatment time indicating that there was no specific timescale set out for cerebral palsy diagnosis. Nine Trusts gave a specific timescale, ranging from 1-2 weeks to 20 weeks, and an average of 10. Blackpool, for example, cited 2-12 week wait for a consultant appointment. Hounslow and Richmond Community Healthcare NHS Trust had a 6 week target for initial assessment. South Tyneside NHS Foundation Trust stated that its team complies with general referral to treatment waiting times, however any child with red flags for cerebral palsy is likely to be seen in 1-2 weeks. Similarly, urgent referrals at The Whittington Hospital NHS Trust are seen within 2 weeks, and within 8 weeks for standard referrals. Of those trusts that responded, Chesterfield Royal Hospital NHS Foundation Trust has a 20 week timescale framework and is the only trust that exceeds the standard 18-week referral to treatment timescale.

Some respondees, East Lancashire Hospitals NHS Trust for example, said that they did not see the need to automatically refer children to the child development service and that some children would simply be referred to the physiotherapist. 20 stated that no timescale was in place. 13 stated that they did not know or collect this data.

4. WHAT IS THE TOTAL NUMBER OF HEALTH VISITORS EMPLOYED BY YOUR TRUST/ HEALTH BOARD?

39 trusts were able to provide an answer to this basic question. Answers ranged from 1 (Southport and Ormskirk) through to 388 (Harrogate and District NHS Foundation Trust). An average of 123 Health Visitors was employed per trust – broadly similar to the average of 114 which was reported in 2016. 27 trusts reported that they employed no Health Visitors, as opposed to the 59 who reported no Health Visitors in 2016. However, this would be typical for some hospital trusts.

5. WHAT IS THE TOTAL NUMBER OF SPECIALIST HEALTH VISITORS FOR CHILDREN WITH SPECIAL NEEDS EMPLOYED BY YOUR TRUST/HEALTH BOARD?

Only 12 trusts responded with a number for the specialist Health Visitors for children with special needs (compared to 27 in 2016). This ranged from 1 to 10.67 (Sussex Community NHS Trust) with an average of 3 specialist health visitors per trust (slightly higher than the 2.16 employed by trusts in 2016/7). 62 responded that they have no specialist Health Visitors compared to 95 in 2016.

6. WHAT TRAINING IS GIVEN TO HEALTHCARE PROFESSIONALS, INCLUDING HEALTH VISITORS AND GPs, TO RECOGNISE THE RISK FACTORS AND POSSIBLE SYMPTOMS FOR CEREBRAL PALSY?

Of all the questions asked of trusts, this question generated the most response, with 60 (nevertheless only 31%) trusts providing information on the different levels and forms of training provided for teams either regularly or as required.

Some trusts, for example Berkshire Healthcare, have given specialist training to Health Visitors, physiotherapists and speech and language therapists. Other trusts include it into ongoing staff development, for example Lincolnshire Community Health Services has a conference every two years for all professionals working with children with cerebral palsy to update them on new developments. Others, including Birmingham Community Healthcare NHS Trust, give therapy staff access to a clinical specialist, a consultant physiotherapist and professional clinical leads. Other trusts reported sporadic training across GP and health visitor populations or 'ad hoc' training provided by community paediatricians upon request. One trust, Central Manchester University, reported that the last training was provided four years ago in 2015.

75 trusts failed to answer whether any training is given to healthcare professionals, including Health Visitors and GPs, to recognise the risk factors and possible symptoms for cerebral palsy. 16 trusts stated that no training is given.

7. WHAT IS THE TOTAL NUMBER OF SPECIALIST STAFF EMPLOYED BY YOUR TRUST/ HEALTH BOARD, WHO ARE TRAINED TO WORK WITH CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY, FROM THE FOLLOWING DISCIPLINES: PAEDIATRIC SPEECH AND LANGUAGE THERAPY, PAEDIATRIC PHYSIOTHERAPY, PAEDIATRIC OCCUPATIONAL THERAPY?

45 trusts gave a figure for the number of paediatric speech and language therapists employed compared to 119 in 2016, and figures ranged from 0 (five trusts reported this) to 68 Whole Time Equivalent (WTE) at Sussex Community NHS Foundation Trust. The average number employed was 17, slightly higher than the 14.5 reported in 2016.

45 also gave figures for paediatric physiotherapists ranging from 1 to 28.3 WTE. The average WTE was 11 across these trusts compared to 9.94 in 2016. 46 trusts gave figures for the number of trained physiotherapists able to work with children and young people with cerebral palsy. The figures ranged from 0 to 24, with an average of 8.7 compared to an average in 2016 of 6.93. 47 trusts gave information on the number of occupational therapists they employed, an average of 9 WTE compared to a 2016 average of 6.93.

78 trusts failed to respond to the question and 16 stated that they did not know or collect the data on the total number of specialist staff employed who are trained to work with children and young people with cerebral palsy from several disciplines.

Only five trusts responded that no staff were trained.

One trust, the Royal Cornwall, also gave details of the number of paediatric dietitians, weight management and paediatric technical instructors.

8. HOW MANY CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY ARE CURRENTLY ON A WAITING LIST TO ACCESS ANY OF THE ABOVE SERVICES WITHIN YOUR TRUST/ HEALTH BOARD?

Only 13 trusts were able to provide a number for children and young people on the waiting list. The number of children and young people with cerebral palsy currently on a waiting list to access services within their Trust was low with nine of the responding trusts reporting waiting list numbers under five. Oxford Health NHS Foundation Trust and Nottinghamshire Healthcare NHS Foundation Trust both had 10 children, Plymouth Hospitals NHS Trust had six. The Heart of England NHS Foundation Trust had 11 waiting for an SLT appointment, three waiting for PT appointment and three waiting for an OT appointment. Whilst these numbers are relatively low, only three trusts responded that they have 0 children on waiting lists.

1. THE TOTAL NUMBER OF CHILDREN AND YOUNG PEOPLE DIAGNOSED WITH CEREBRAL PALSY IN YOUR LOCAL AUTHORITY POPULATION AREA WITHIN THE LAST FIVE YEARS.

Just six out of 408 local authorities responded with a number of children and young people diagnosed with cerebral palsy in their local area. 145 other authorities responded to say that the information was not easily obtainable. Answers ranged from 36 to 165 with an average of 114 – significantly higher than results from the 2016 survey which found that the average number of children and young people diagnosed (taken from a similarly small sample of seven local authorities) was 28.

Name of Local Authority	Number of Children diagnosed in Local Authority area
Southend	165
Hampshire	138
Hertfordshire	124
Essex	112
East Sussex	111
Northumberland	36

2. WHAT IS THE CARE PATHWAY FOR CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY IN YOUR LOCAL AUTHORITY? PLEASE PROVIDE A COPY OF THIS IF POSSIBLE.

136 of those local authorities responding to the question said they were unable to provide the information requested. 14 (only 3.4%) did respond with a range of answers ranging from following the NICE guideline for cerebral palsy, ways to improve access to physiotherapists including open clinics or advice booklets for GPs and Health Visitors, and allocating a specific local authority team to discuss the care needs with the child's family to providing a full diagnosis and care pathway led by the local Child Development Centre. Three of those giving detailed answers said they provided no specific care pathway.

3. WHAT IS THE NUMBER OF CHILDREN AND YOUNG PEOPLE REFERRED TO SPECIALIST CENTRES AND VOLUNTARY AGENCIES BY YOUR LOCAL AUTHORITY FOR TREATMENT AND MANAGEMENT OF CEREBRAL PALSY?

151 responded but only two of those provided information. One, Doncaster, said that when symptoms were identified, children were referred to a General Development Assessment clinic. The response went on to say that waiting times for the clinic varies from 9-14 weeks, but if a child referred was under the age of 18 months the child would be seen as an urgent referral. Hampshire said that children were seen in the developmental clinic if they were ex-neonatal babies and would be seen at regular intervals to monitor their development.

4. HOW MANY CHILDREN AND YOUNG PEOPLE HAVE CEREBRAL PALSY LISTED AS A DISABILITY ON THEIR EDUCATION, HEALTH AND CARE PLAN?

19 local authorities (4.6% of the total) responded to the question, with 131 responding to say that the data was not available. The number of children listed with cerebral palsy as a disability on their Education, Health and Care plan varied from 3 (in Tameside) to 105 in Oxfordshire (an outlier) with an average from this sample of 48. In 2016, 19 local authorities submitted information about the number of children with cerebral palsy listed on their EHCP. At that point, in the two years since the EHCP had been created the average number of care plans issued was four suggesting a significant increase in Education, Health and Care Plans in this time, perhaps as the local authorities have adjusted to the requirements of the 2014 legislation.

One local authority, Stockport, responded to say that they did not hold a specific category of cerebral palsy within Education, Health and Care Plans but that there were 62 listed as having a physical disability. This demonstrates a lack of understanding of the significant impact that cerebral palsy, as a neurological condition, has on all aspects of childhood development, not just physical.

5. HOW MANY CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY: HAVE BEEN TRANSFERRED FROM SEN STATEMENTS TO EHC PLANS SINCE 2014? ARE ON THE WAITING LIST TO BE TRANSFERRED FROM A SEN STATEMENT TO AN EHC PLAN?

15 local authorities (3.65%) were able to provide a number for children and young people transferred over from SEN statements to EHCPs, with a range of 2 to 64 and an average of 42. Only one local authority, Bexley, said they were waiting to transfer someone from the SEN statement to the EHC Plan. The 2016 survey found that the average number of transfers was 5.4 – again suggesting a significant increase across the two years which is to be expected as authorities implement the new system. Of those local authorities who did reply, 136 told us they did not have access to information.

6. WHAT TRAINING IS GIVEN TO HEALTHCARE AND EDUCATION PROFESSIONALS EMPLOYED BY YOUR LOCAL AUTHORITY, INCLUDING HEALTH VISITORS AND SCHOOL NURSES, TO RECOGNISE THE RISK FACTORS AND POSSIBLE SYMPTOMS FOR CEREBRAL PALSY?

24 local authorities were able to respond with details of training to education and healthcare professionals in their area (as opposed to nine in 2016).

Whilst teachers were rarely trained, most responses said that Health Visitors and school nurses did receive specialist training in child development and numerous responses highlighted recourse to various professionals including the community nursing team, community paediatricians, occupational and physiotherapists or a physical disabilities team. However, a number of local authorities referred to general training for children with physical disabilities rather than training specific to children with cerebral palsy.

One council, Bromley, said that cerebral palsy was covered in a Children's Emotional and Additional Health Needs module designed for Health Visitors and school nurses' professional development. Salford also stated that their community paediatricians have been trained to diagnose and manage children with cerebral palsy and they provide teaching to specialist trainees. Gloucestershire informed us that the Council's Advisory Teaching Service was able to provide advice to any education professional working with a child with cerebral palsy and Swindon indicated that they had a number of education and health professional roles whose training included identification of risks and possible symptoms of developmental disorders such as cerebral palsy.

7. WHAT INFORMATION ON SERVICES PROVIDED FOR CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY IS EXPLICITLY STATED IN YOUR LOCAL OFFER? IF NONE, WHAT PLANS DOES YOUR LOCAL AUTHORITY HAVE TO REVIEW THE LOCAL OFFER TO INCLUDE THIS INFORMATION?

Only 3 local authorities (0.7%) were able to name services included in their local offer which specifically cater for to children with cerebral palsy. One council, Sheffield, said that the local offer had a specific filter for cerebral palsy which was able to provide information services to support families of young people with cerebral palsy.

Other councils indicated that they did not have specific groups but mentioned some inclusive groups that would be suitable for children with cerebral palsy or that covered physical disabilities as a general group. Some of these local authorities said that they were in the process of reviewing the Local Offer provision. The results are a marked decrease from the 2016 survey, of which 46 local authorities were able to say that they included cerebral palsy in their Local Offer.

8. PLEASE PROVIDE A LIST OF ORGANISATIONS WITHIN YOUR LOCAL AUTHORITY AREA WHICH PROVIDE SPECIALIST TREATMENT (E.G. CONDUCTIVE EDUCATION, BOBATH THERAPY, ETC.) FOR CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY.

18 local authorities gave information about the organisations in their area providing specialist treatment, a marked decrease from the information gathered in 2016, which saw 39 local authorities give information about the services available.

Kensington and Chelsea Council said: 'the council does not maintain any provisions which offers conductive education as an approach or Bobath Therapy and we are not aware of any non-maintained sector providers in this area. We believe that there may be some Bobath-trained NHS physiotherapists but we do not hold records of these.'

9. PLEASE PROVIDE A LIST OF EDUCATIONAL ESTABLISHMENTS OUTSIDE OF YOUR LOCAL AUTHORITY AREA THAT CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY, WHO RESIDE WITHIN YOUR LOCAL AUTHORITY AREA, ATTEND TO RECEIVE SPECIALIST EDUCATION.

30 local authorities were able to provide information about education establishments outside of their local authority area. Some, Brent and Lewisham for example, were able to provide a long list of schools in the surrounding areas. Others, including Gateshead, Northumberland and Portsmouth were only able to name one school suggesting that some families might have to travel a significant distance for their children to access these services.

A total of 26 Health Boards were contacted across the devolved nations and the 17 responses again paints a varied map of care, both in terms of the care provided cross-nation and inter-nation. Seven Health Board in Wales were contacted and four responded. Five Health Boards in Northern Ireland were contacted and three responded. 14 Health Boards in Scotland were contacted and 10 responded. Scottish responses were the most detailed.

SCOTLAND

Broadly speaking, Scottish health boards were better at responding to the requests than the other devolved nations.

The recognition of the risk factors of cerebral palsy is taught as a core element of university training courses to become an occupational therapist. NHS Lothian stated that all therapists will have training in working with children with cerebral palsy at an undergraduate level and that Specialist and Highly Specialist Therapists have access to a wide range of training, with some of it specific to cerebral palsy. Lothian also stated that all children with cerebral palsy, whether currently receiving physiotherapy intervention or not, will be offered an annual Cerebral Palsy Integrated Pathway for Scotland (CPIPS) assessment to ensure issues and concerns are picked up. NHS Tayside also stated that all GPs cover cerebral palsy clinically as part of their training, whether that be during paediatrics, community paediatrics, neurology or out of hours training. Whilst there is no specific training in cerebral palsy, Health Visitors and medical students are trained in neurodisability.

Of the 14 Scottish health boards contacted, 10 responded with information, and of those, five responded with a specific pathway. These varied in a range of detail: NHS Ayrshire & Arran stated that once a child has a diagnosis of cerebral palsy, they will follow the guidelines of Cerebral Palsy Integrated Pathway for Scotland (CPIPS) in accordance with the national pathway. Information is put into a national database and remains ongoing from the age of two. Ayrshire & Arran has a multi-disciplinary neurodevelopmental follow up clinic and all children receive a pelvic x-ray at two, six and sixteen years. All pre-term babies are screened at the

Ayrshire & Arran Board at a neurodevelopmental clinic and are assessed using the Bayley III assessment. Should concerns emerge from these objective assessments, the child will be referred at the earliest possible opportunity. The neurodevelopmental clinic is also supported by speech and language therapy with a targeted service, and there is, in place, a specific care pathway ensuring that children are followed up at 1, 3, 6, 12 and 24 months. In terms of training given to healthcare professionals, including health visitors and GPs, to recognise risk factors and possible symptoms, Ayrshire & Arran therapists have the competencies to assess and make a differential diagnosis of speech, language and communication needs and the appropriate interventions of support in their core team, with speech and language therapists with specialist skills in Dysphagia and management of eating, drinking and swallowing, as well as Augmentative and Alternative Communication Systems.

NHS Lothian does not have a specific care pathway, but any request for assistance for a child with cerebral palsy is assessed and a range of interventions provided based on the child's needs at the time. This could range from a phone call with parents or school, to a hands-on assessment of the child at school/nursery or home. The pathway will be determined by the needs of: the child, the family and the school and is based on a collaborative approach and 'Getting It Right for Every Child' (GIRFEC) principles. At Lothian there are 63 headcount paediatric physiotherapists and very few will not have skills in treating children with cerebral palsy, and whilst there are no SLTs which specialise exclusively in cerebral palsy, there are physiotherapy staff with highly specialist skills in treating patients with neurological disorders.

Scottish health boards, either did not respond or did not employ Specialist Health Visitors, and there was a range of figures for Health Visitors. In Tayside there are 169.13 WTE and in Ayrshire & Arran there are 131.61 WTE Health Visitors, whereas in Shetland there are only 8.28 WTE, and in Western Isles there are only 11.65 WTE. This demonstrates that even within Scotland there remains a variety of provision depending on geographic location.

Scottish Boards were able to provide more information about the routes provided. NHS Grampian aims to see children within 12 weeks of referral, and at NHS Greater Glasgow and Clyde, children referred with concerns regarding possible evolving motor disorder will be seen by a nurse within 28 days of referral and prioritised for multi-professional assessment as part of their Joint Assessment Clinics within each local Child Development Centre. This route is followed by NHS Western Isles.

Only five devolved Boards responded with numbers of those children diagnosed with cerebral palsy, ranging from 456 at Lothian, 362 at Greater Glasgow and Clyde, and 3 at Shetland. **It is clear from the evidence provided, however, that Scotland demonstrates a better overall provision of specialist care than the other UK nations.**

Out of all 14 Scottish Health Boards asked, 10 did not respond when asked how many children or young people are waiting for access to services. The remaining responses from NHS Ayrshire & Arran NHS Dumfries and Galloway, NHS Western Isles and NHS Shetland all stated that there were no children or young people on their waiting lists.

The provisions for including cerebral palsy in the undergraduate and training of Scottish professionals is clear both in the quality and the number of responses, and it is **disappointing that Scotland is the only of the four nations that is able to provide consistent and substantial detail in the provisions of care and support.**

NORTHERN IRELAND

Of the Trusts in Northern Ireland that responded, it was clear that there is still a lack of a specific care pathway. Southern Health and Social Care Trust stated that there is a generic Child Development Clinic care pathway, as well as a detailed regional physiotherapy care pathway for children with cerebral palsy. Belfast Health and Social Care Trust states that it follows NICE guidelines.

Both Belfast Health and Social Care Trust and South Eastern Health and Social Care Trust claimed that they did not collect or record data on waiting lists, and only Southern Health and Social Care Trust stated that there are currently no children on a waiting list. The other Trusts did not respond with this information.

South Eastern Health and Social Care Trust responded to the request but stated that it either does not collect the information required, has no specific care pathway or provide any specific training to groups of staff. It stated that the total Health Visitors numbers 74 and that it has no Specialist Health Visitors for children with special needs. No Northern Irish Health and Social Care Trust employs any Specialist Health Visitor, but Belfast Trust does fund 77.20 WTE Health Visitors and Southern Trust employs 96.07 WTE Health Visitors.

In Northern Ireland, only three of the five Trusts who responded to our audit provided a response when asked what care pathway exists. South Eastern stated that they did not have the information, and Southern and Belfast Trusts stated that there is no specific timescale or separate referral route.

WALES

Out of all the Welsh Health Boards, only Powys Teaching Board provides specific training to healthcare professionals, including Health Visitors and GPs, to recognise the risk factors and possible symptoms of cerebral palsy. Of the Welsh Boards that responded, only Hywel Dda University Health Board (UHB) responded that it is currently developing a unified care pathway for children and young people, although it does not currently deliver any formal training for recognising the risk factors and symptoms of cerebral palsy. This is regularly discussed within Community Paediatric meetings, however, and the UHB has diagnosed 546 patients with cerebral palsy within the last 5 years.

Other Welsh Boards either stated that they offer no overarching care pathway, or did not respond to the request. Powys Teaching Health Board stated that it did not have a specific timescale in its current care pathway but that all paediatric therapies work to a referral to treatment pathway of under 10 weeks. Health Visitors also work closely with paediatric physiotherapists and refer for early assessment, with early intervention training. Powys also has 10 paediatric physiotherapists, 2 paediatric OTs and 2 paediatric SLT staff with varying degrees of expertise in cerebral palsy. Unfortunately, data on how many Welsh children and young people are on a waiting list to access services is limited with only two responses: Betsi Cadwaladr University Health Board stated that there are under five, and Powys Teaching Health Board stated 0. The other boards did not respond with this data.

In contrast to Scottish health boards, Welsh boards either stated that there is no overarching care pathway or did not respond to the request. Powys Teaching Health Board stated that it did not have a specific timescale in its current care pathway but that all paediatric therapies work to a referral to treatment pathway of under 10 weeks.

As in 2016, the vast majority of the CCGs contacted in 2018 about their provisions for cerebral palsy did not respond, which remains disappointing. 42 responses were received and of those that did, only six responded with any information, data or figures which could be used effectively to map out the wider CCG approach to provision for children and young adults with cerebral palsy. The lack of responses is a continuation of the data collected in 2016, which disappointingly, shows that there has been little progress in even attempting to collate the data. Figures are down regarding those CCGs gathering numbers of children and young adults diagnosed with cerebral palsy, down from 12 in 2016.

NHS Eastern Cheshire CCG and NHS West Cheshire CCG were the only two CCGs which were able to provide data on the total number of children and young people diagnosed with cerebral palsy in the last five years, detailing a total of 57 and 41 respectively. For comparison, NHS West Cheshire CCG recorded 121 children and young people diagnosed with cerebral palsy in the five years preceding the 2016 Report. The CCGs did not provide any additional information, although NHS West Cheshire CCG did state that it does not have a specific pathway for children and young people with cerebral palsy, but that referrals will be actioned in accordance with the standard 18-week referral to treatment guidelines. Two responses out of all CCGs contacted falls below what could be reasonably expected in providing even basic data about the numbers of children and young people with cerebral palsy who have been diagnosed.

Whilst NHS Medway CCG failed to record the number of children and young people diagnosed in the past five years with cerebral palsy, it informed us that services for children and young people with cerebral palsy are provided as part of the Medway Integrated Children's Community Health Service. The integrated service provides care for children aged 0-19 and ranges from universal health provision to specialist care such as that provided by paediatricians and therapists. Children with cerebral palsy are case loaded on the neurodisability pathway, which aims to maximise self-care and independence and reduce risks of harmful deterioration. At NHS Medway CCG, services are overseen by specialist practitioners and integrated with universal services, which includes emotional and wellbeing support and joint visits by therapy and public health nursing practitioners under a single care plan. Services are subject to 18-week referral to treatment standards. At NHS Medway CCG, there are no Health Visitors or Specialist Health Visitors employed by the CCG, or any specialist staff who are trained to work with children and young people with cerebral palsy.

NHS West Essex CCG similarly did not record the number of children and young people diagnosed in the past five years with cerebral palsy. Children will be referred by their GP to the child development service, the timescale of which is dependent on individual GP administrative process. Provider organisations and GP practices are responsible for ensuring the training needs of their staff are met, and training may be offered by the provider of West Essex Children's Community Health Services where required. NHS Warrington CCG does not have a specifically-commissioned pathway of care for children and young people with cerebral palsy, but this is included within their Acute and Community Contracts for Paediatrics.

NHS North Lincolnshire CCG does not commission a specific cerebral palsy pathway, but those children and young adults with signs and systems of cerebral palsy will be referred to Secondary Care Paediatrics. For pre-school children, they are sometimes referred onto the Child Development Centre Neurodevelopmental Service pathway. The current pathway at NHS North Lincolnshire CCG involving a referral to paediatrics should occur within 18 weeks from referral to assessment.

NHS Herts Valley did not collect any data around cerebral palsy but did state that it has not provided training to recognise the risk factors and possible symptoms for cerebral palsy.

This shows that much more remains to be done at even a basic level in the recording of cerebral palsy by CCGs. It is disappointing that more has not been done to make improvements between the 2016 and 2018 Reports and that cerebral palsy provision continues to be neglected. It is only by implementing a thorough recording system that CCGs can begin to address the issues that face children and young people with cerebral palsy, and it is disheartening that even the recording of the current systems in place is severely limited. Extremely limited information is received on the level of cerebral palsy training available to health professionals, or as to the specialist providers from whom children with cerebral palsy could receive care. It remains the case that the service available even in major conurbations, such as London and Manchester, is extremely poor, as well as in rural areas.

The fact that only six CCGs were able to provide even limited information as to the total number of children and young people diagnosed with cerebral palsy in the last five years, the care pathways for those with cerebral palsy, or the number of Health Visitors and specialist Health Visitors raises questions as to how much awareness there is of the needs of children with cerebral palsy and their families within local areas.



CONCLUSION: THE WAY FORWARD

Both the 2017 and 2019 Reports commissioned by Action Cerebral Palsy have demonstrated that progress on cerebral palsy provision has stalled since the 2015 Parliamentary Inquiry highlighted the need for drastic improvements. Both reports reveal that basic information, such as the number of children diagnosed with cerebral palsy, access to general or specialist healthcare professionals or whether a care pathway is available, are not held centrally or recorded in any meaningful way.

It remains disappointing that, even after four years and two reports following the 2015 Parliamentary Inquiry, only 10% of NHS trusts confirmed that they had a specific care pathway for children and young people with cerebral palsy. The majority of NHS trusts and local authorities are still not using measures available to monitor need, provision and services.

The levels of care remain highly variable across England and the devolved nations and only a small minority of trusts even outlined the need for a distinct cerebral palsy care plan. Of those that did, most were still in the process of being implemented. It is unacceptable that the families of those affected by cerebral palsy are let down by services and that a postcode lottery of arbitrary and generic care plans remains the standard.

Looking to the future of cerebral palsy provision, the formation of a national UK Cerebral Palsy Register is key. It is only by having the recorded information made available that progress and improvements can be measured and held accountable for.

Action Cerebral Palsy believes that the introduction of a UK Cerebral Palsy Register will be integral to better and earlier provision and end the national scandal that is currently in place. We call for a nationally-implemented integrated education and health pathways for children with cerebral palsy to ensure best practice, early intervention and a holistic approach.

Action Cerebral Palsy maintains the view that alongside the creation of a national UK Cerebral Palsy Register, GPs, health practitioners and teachers must be equipped with specific knowledge on cerebral palsy, as well as more done to champion earlier detection, diagnosis and intervention.

As highlighted by this report, Scotland has done better in providing an overall provision of specialist care than the other UK nations. The variation of care both within nations and across the UK suggests that the postcode lottery of services remains a major issue.

Although there has been a slight improvement in access to trained education and healthcare professionals and in training made available to GPs and Health Visitors since 2015, the lack of identification, integrated and managed pathway means there is an absence of proper monitoring and allocation of funding to the right services. We hope that this second report will demonstrate that there is still a need to help every child and young person in the UK with cerebral palsy to access, from birth, the best possible intervention, care, education and support.

ABOUT ACTION CEREBRAL PALSY

Action Cerebral Palsy was formed in 2013 as a consortium of specialist centres that provide services for children with cerebral palsy. It is now an active, independent campaigning charity that seeks to represent the cerebral palsy community. Of particular importance, Action Cerebral Palsy seeks to raise the profile of, and to address the challenges facing, children with cerebral palsy and their families, and to be a voice for this under-represented group.

Our vision is that every child and young person in the UK with cerebral palsy is able to access, from birth, the best possible intervention, care, education and support to meet their complex and changing needs.

Action Cerebral Palsy works towards improving public, professional and political awareness of cerebral palsy and to develop and improve models of best practice at a local and national level.

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◎ APPENDIX: ABOUT CEREBRAL PALSY

DEFINITION AND PREVALENCE

Cerebral palsy is a motor disorder 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, cerebral palsy is a condition that can affect those from all social backgrounds and ethnic groups. The condition is the most common physical disability 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 palsy. 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 limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems”. (Rosenbaum et al. 2007)

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 described by the way in which the lesion affects the messages to the muscles, as determined by the area of the brain affected:

Spastic cerebral palsy (affecting c.90% of individuals with cerebral palsy²)

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 cerebral palsy (c.5%²)

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.

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

² Reid S., Carlin J., Reddihough D. (2011); Distribution of motor types in cerebral palsy: how do registry data compare?, Dev Med Child Neurol 53:233-238

Ataxic cerebral palsy (c.5%²)

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.

Cerebral palsy can also be classified according to the parts of the body affected:

- **Hemiplegia** – affecting one side of the body (38% of cases³)
- **Diplegia** – affecting lower limbs (36%)
- **Quadriplegia** – affecting all four limbs (26%)

While the above definitions serve the ‘medical’ world they do not give a clear picture of the challenges or nature of living with this condition. Cerebral palsy is seen as medically non-progressive however the wider impact of having the condition may not be. 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 is a condition that originates before birth or in very early childhood, 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 palsy will be hindered, to varying degrees, in the process as they battle to learn fundamental skills related to symptoms. Therefore, cerebral palsy should, to a significant extent be considered as a problem of ‘learning’ rather than a problem of functioning or communicating.

Children with cerebral palsy 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.

³ Based on the Report of the Australian Cerebral Palsy Register (2009) and likely to be representative of experience in the UK (which does not have a national register)

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 palsy 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, cerebral palsy encompasses a number of neurological disorders which can affect all aspects of development in the young child. Therefore, cerebral palsy should not be considered as just a physical disability, 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 cerebral palsy cannot be cured, early intervention and intensive therapy can substantially mitigate its impact. With appropriate intervention, the weight of recent neuroscientific 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. Neuroplasticity is particularly important in relation to cerebral palsy 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 which 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 palsy 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 palsy to hopefully restore sensorimotor functions or at least prevent further degradations.

Through early intervention, infants and young children with cerebral palsy can be helped to develop more normal 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 which would otherwise fall both on the state and the voluntary sector.

RISK FACTORS AND DIAGNOSIS

Risk factors which might result in cerebral palsy 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

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 palsy, *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

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 palsy. 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 palsy, 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., 2011⁸). Given the critical importance of early intervention, families' experiences of assessment and diagnosis have formed a key part of this inquiry to date, 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 palsy, such as the *Qualitative Assessment of General Movements (GMs)* and the *Hammersmith Infant Neurological Assessment*. We are hopeful that these models will be applied as best practice, detection, and diagnosis of cerebral palsy across the United Kingdom.

⁹ Badawi N., Felix J., Kurinczuk J., et al. 2005. Cerebral palsy 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 palsy 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 palsy: neonatal predictors for low-risk term singletons. *Pediatrics* 127:e667-e673.

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