

## **Action Cerebral Palsy - Written evidence (PRT0006)**

Action Cerebral Palsy is the only UK charity campaigning specifically on behalf of children with cerebral palsy (CP) and their families. We were alerted to this Call for Evidence by Professor Neena Modi, the renowned neonatologist who we are proud to have as a trustee of the Charity.

It is estimated that 1 in 400 babies born in the UK have a type of CP, a lifelong complex neurological condition which primarily affects muscle tone, but which can also impact on many aspects of childhood development, health and wellbeing. The impact of CP on an individual can range from mild impairment to profound disability. The Office for National Statistics figures indicate that with a birth rate in England and Wales of around 700,000 per year there may be as many as 1,700 new cases of cerebral palsy in children each year.

Action Cerebral Palsy sponsored the All-Party Parliamentary Group on Cerebral Palsy which resulted in the report ***Early identification, intervention and pathways of care of infants and young children with cerebral palsy: The case for reform and investment, March 2021*** from which much of the evidence in this submission is taken.

### **1. Primary prevention and treatment for preterm birth – pre-term birth as a significant risk factor for cerebral palsy**

Preterm birth is a significant risk factor for cerebral palsy, the most common child onset lifelong neurological condition, with the risk increasing with decreasing gestational age. A comprehensive meta-analysis by Himpens et al including 25 studies reported the **prevalence of cerebral palsy as 14.6% (95% CI: 12.5–17) at 22–27 weeks' gestation, 6.2% (4.9–7.8) at 28–31 weeks, 0.7% (0.6–0.9) at 32–36 weeks and 0.1% in term infants.** (*Developmental Medicine & Child Neurology 2008, 50: 334–340.*)

**Prevention of preterm birth at any stage of gestation is therefore critical to reduce the risk of neurological damage including cerebral palsy.**

## **2. Variations in care and longer-term impacts, care and support for pre-term babies and their families.**

The Quality standard from the Developmental follow-up of children and young people born preterm Published: 18 May 2018

[www.nice.org.uk/guidance/qs169](http://www.nice.org.uk/guidance/qs169) included the following recommendations:

- *Parents or carers of a preterm baby who is eligible for enhanced developmental support are provided with a single point of contact for outreach care within the neonatal service.*
- *Children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up appointments in the first year and an assessment at 2 years that focus on development.*
- *Children born before 28+0 weeks' gestation have a developmental assessment at 4 years.*

The APPG on Cerebral Palsy sessions on early identification, intervention and pathways of care of infants and young children with cerebral palsy in 2020 heard evidence from families and clinicians that the experience of many families **falls far short of these standards** and that there is too much variation in early identification and intervention across the country.

The APPG found that "*Intensive early intervention for infants with cerebral palsy remains the exception, rather than the norm, across the UK, despite a great deal of evidence in its favour. Both NHS and voluntary care providers are often under-resourced and struggle to deliver intervention at the level of scale and intensity that is needed. Up to 50% of all infants with cerebral palsy are not identified as being high risk for the condition at birth, and their needs are not addressed through any developmental surveillance scheme as they grow. Where children are identified as high*

*risk for cerebral palsy at the pre- or postnatal stage, their development is more likely to be monitored. The NICE Cerebral Palsy Guidelines provide clear direction on referral, assessment, and diagnosis, but are, crucially, not mandatory. Systems for surveillance are similarly not sufficiently robust, and it falls upon the parents of the remaining 40-50% of children who go on to be diagnosed - but are not identified as high risk for cerebral palsy beforehand - to raise any concerns with health professionals".* **Early identification, intervention and pathways of care of infants and young children with cerebral palsy: The case for reform and investment, March 2021)** p.5

<https://actioncp.org/wp-content/uploads/APPG-on-Cerebral-Palsy-report-2021.pdf>

Factors contributing to late identification and intervention are;

**1. Inadequate screening for developmental delay and lack of awareness of the signs of cerebral palsy in primary health professionals**

*The APPG on CP report found that "there are often unnecessary delays in the early identification and referral of infants, which, in turn, prevents effective early intervention treatments taking place at the time when they can be the most impactful. A key reason for this is a lack of awareness of the early presenting features of cerebral palsy amongst primary healthcare professionals (including a "wait and see" attitude) as well as the general public. Additionally, records of child development should provide a better framework for monitoring signs of cerebral palsy. The personal child health record, or 'red book', should be modified to check for signs of abnormal motor development, as a practical tool to support parents and health visitors to know and look out for signs of cerebral palsy, and enable more rapid onward referral."*

The APPG on cerebral palsy was informed that, "All children in England receive five mandated health visiting reviews currently. These are: antenatal, 10-14 days, 6-8 weeks, 9-12 months, and 2-2.5 years.

*Through these reviews, health visitors play a crucial role in the early identification of children with atypical development patterns or impairments likely to result in disability. However, health visitors currently do not conduct a baby's first developmental assessment until the 9–12-month review. This means that there is no mechanism to routinely assess younger infants for developmental difficulties when they first begin to show these signs. Detection of cerebral palsy at twelve months will often mean that valuable time for impactful intervention has been lost, which will impact that baby throughout its life. In particular, a visit at three months old could be crucial in identifying early signs of abnormalities and facilitating swift and timely referral”.*

*The APPG proposed that “there should be three additional universal contacts, to increase the opportunity for early detection of children with cerebral palsy. These should take place at 3-5 weeks, 3 months, and 3.5 years. Increased universal developmental monitoring in this way will provide a vital safety net for babies and families and help identify infants with cerebral palsy at an earlier juncture, which could be crucial to earlier and better interventions. In addition, infants who are at high risk of cerebral palsy should receive additional support and monitoring via a high-quality, standardised national surveillance programme.*

## **2. National decline in the Health Visiting Service**

*The APPG found that, “Health visitors are a highly skilled workforce and are well-equipped to work in partnership with parents and communities to improve early identification and intervention for infants with cerebral palsy via their role in the Healthy Child Programme. The health visiting service also provides a vital safety net for vulnerable babies and families and is an integral tool in improving outcomes. Health visitors can play a crucial role in mitigating some of the known risk factors for cerebral palsy. This includes supporting mothers to prepare for a healthy pregnancy and reduce the prevalence of preterm birth, promoting immunisations and*

*early detection of neonatal risk factors, and promotion of accident prevention advice to parents to reduce traumatic brain injury”.*

However, the 2023 State of Health Visiting, UK survey report <https://ihv.org.uk/wp-content/uploads/2024/01/State-of-Health-Visiting-Report-2023-FINAL-VERSION-16.01.24.pdf> found that there is a health visiting workforce crisis in England and currently an estimated shortage of 5,000 health visitors in England, a decline of more than 40% of the workforce since 2015. This means that there are not enough health visitors to meet the scale of rising need and to provide crucial support, surveillance and screening of “at risk” infants and their families. The APPG report concluded that ***“The Government must urgently invest in the health visiting workforce to increase its size and capacity and offer specialised training in the early signs of movement difficulties in infants, to ensure health visitors have the tools to identify signs of cerebral palsy as early as possible.”*** *Early identification, intervention and pathways of care of infants and young children with cerebral palsy: The case for reform and investment, March 2021*) p.5 <https://actioncp.org/wp-content/uploads/APPG-on-Cerebral-Palsy-report-2021.pdf>

### **3. Unacceptable variation in pathways of referral and care across the UK.**

The APPG on Cerebral Palsy found that *“rapid referral for onward specialist assessment when an infant is identified as showing signs of cerebral palsy is imperative. The current standard 18-week referral-to-treatment timescale is too long, and wastes precious early weeks and months of neuroplasticity, when interventions can have the greatest impact. Families need to know that when they raise concerns, there will be a sense of urgency in referral for full assessment and access to best practice intensive intervention”.* P.7

Action Cerebral Palsy’s *Variations in Care* report, 2018

<https://actioncp.org/wp-content/uploads/VARIATIONS-IN-CARE-TWO->

[YEAR-REVIEW.pdf](#) found that very few healthcare trusts had a rapid referral timescale for infants with signs of cerebral palsy, despite the need for this provision to be the standard across the UK. The NICE Guidelines **Cerebral palsy in under 25s: assessment and management** NICE guideline [NG62] Published: 25 January 2017, state that *"an enhanced clinical and developmental assessment and follow-up programme should be provided for all infants and children who are at risk of cerebral palsy and who show abnormal movements, posture, tone or late development of motor skills"*. However, the APPG on cerebral palsy found that *"there is currently an unacceptable level of geographical variation in access to best practice early detection, referral, diagnosis and intervention for infants with or at risk of cerebral palsy in the UK. This is compounded by variations in the support that families receive from the health visiting service based on where they live. The impact of this is enormous. Opportunities for children and families are lost forever, due to being unable to access appropriate, specialised care. The chance to reduce the cost to the public purse by ensuring optimal interventions, pathways and outcomes in terms of future education, health and social care of these children is also lost. Without this vital intervention, precious time will be lost, and the effect of the brain damage and sensory-motor impairment will start to impact on the young child's ability to learn from their environment through play and the normal activities of early childhood, including language and communication."*

*The NICE Guidelines and Quality Standards already provide a toolkit for national standards for identification, referral, and pathways of care for infants at risk of or with cerebral palsy. Clinicians in regional centres of excellence for neurodisability already have the skills and expertise to create high quality pathways for children and their families. The APPG report concluded; "All health authorities should be required to implement the NICE Guidelines and Quality Standards as a minimum requirement. All practitioners and clinicians at a local level must be fully aware of their*

*responsibility for prompt referral to expert multi-disciplinary teams. To implement this, the Government must fund and ringfence streamlined pathways of care for children at risk of neurodisability. This should lead to the establishment of properly mapped out, costed, and funded national care pathways, between primary to secondary and tertiary care, and include agreed and audited quality standards. Referral to-treatment timescales must be tightened and minimised to facilitate rapid intervention at the earliest possible stage. Where there is inadequate provision or lengthy waiting times within the local statutory sector, health services for assessment and intervention, families should have access to expert services provided by the private or voluntary sector.”* **Early identification, intervention and pathways of care of infants and young children with cerebral palsy: The case for reform and investment, March 2021)** p.7. <https://actioncp.org/wp-content/uploads/APPG-on-Cerebral-Palsy-report-2021.pdf>

**Action Cerebral Palsy is heartened by the work of the NHSE CYP Transformation team on cerebral palsy which is developing a model for commissioners to ensure standard pathways of care for children with cerebral palsy and we call upon the UK Government to support the recommendations of this group when they are published.**

### **Care and support for families**

*The APPG on Cerebral Palsy heard that "Parents of children with cerebral palsy face a deeply challenging and stressful situation. Not only do they have to endure uncertainty about their child's health, but they must also navigate multiple services with many different access points, and often have to fight at each point of entry to secure what their child needs. This has a detrimental effect on mental health and wellbeing and often leaves parents exhausted, meaning that the more resilient and resourced parents are the only ones who have the energy to seek out appropriate provision for their child and so bringing about negative social mobility*

*outcomes. Parents need clarity on what appropriate provision for their child should look like, especially immediately after diagnosis. It is unclear to parents what "good" looks like when navigating an incredibly complex system.*

*Many families report lack of proper explanation of their child's condition by professionals, inadequate signposting that does not include voluntary services, and inconsistent early therapy input. This means that more financially resilient families tend to seek out further appropriate provision, whilst the most vulnerable are more likely to accept the less intensive intervention that is too frequently offered as the default. Compounding this is the fact that families with more financial resources are able to access more intensive private or charitably subsidised provision, creating significant inequalities in outcomes. This disparity is crucial to acknowledge, considering children from disadvantaged backgrounds are disproportionately represented within the population of children with SEND. Families require better grassroots support from expert professionals who can empower them to ask questions and receive honest advice and support."* **Early identification, intervention and pathways of care of infants and young children with cerebral palsy: The case for reform and investment, March 2021)** p.9.

<https://actioncp.org/wp-content/uploads/APPG-on-Cerebral-Palsy-report-2021.pdf>

These APPG findings were again articulated by parents of children with CP who participated in consultation forums held by the NHSE CYP Transformation Team on Cerebral Palsy in Autumn 2023.

To address this lack of co-ordination and provide a trusted neutral lead professional, the APPG recommended that, *"When navigating the assessment and diagnostic process, each family should be assigned a "partner" within each child development team or from a specialist voluntary provider. This partner could be any qualified professional with knowledge of cerebral palsy who is able to provide monitoring, in-reach,*



*information, and support to the family, and help them to refer to and co-ordinate services. (p.9) In later APPG sessions, the co-ordination role of a lead professional to act as a neutral advocate throughout the child's educational years was also recommended Best Practice in Education, Health and Care Plans (EHCPs), Teaching, and Learning for Children with Cerebral Palsy: The case for quality provision and standardisation p.9*  
<https://actioncp.org/wp-content/uploads/EHCP-report-APPG-on-Cerebral-Palsy-October-2021.pdf>

### **Learnings from other countries around the world including data collection and research**

**The Australian Cerebral Palsy Alliance (ACPA)** are world leaders in the prevention, early detection, intervention and advocacy of cerebral palsy. The Cerebral Palsy Alliance Research Institute <https://cerebralpalsy.org.au/research/> has driven research into the causes and prevention of cerebral palsy (including prematurity) and informed best clinical practice from pre-birth.

### **There has been a subsequent marked decline in the rates of cerebral palsy diagnosis as monitored and recorded by the exemplary Australian Cerebral Palsy Register (ACPR).**

The ACPA website page <https://cerebralpalsy.org.au/research/research-projects-priorities/cp-register> states that the ACPR is a confidential research database of clinical information about people with cerebral palsy. The aims of the CP Register are to monitor and report the changing rates of cerebral palsy, gain further understanding about the causes of cerebral palsy, evaluate preventive strategies and assist in planning services for children and adults who have cerebral palsy.

The ACPR group regularly publishes reports to update the cerebral palsy community about trends in the rate and severity of cerebral palsy. The 2023 Australian CP Register Report includes data from almost 11,000 people with cerebral palsy in Australia. Key findings of the report include:

- **The rate of CP has fallen to 1.5/1,000 live births – the lowest in the world. This means that one in 700 children in Australia are born with CP, a sustained decrease of around 40% from just twenty years ago.**
- While the majority of children with CP live in major cities, 30% live in regional, rural or remote Australia, highlighting the importance of equitable and culturally safe access to services.
- Over the last 20 years, the number of children requiring assistive technology for mobility (such as walkers and wheelchairs) has fallen from 0.8/1,000 to 0.5/1,000, indicating that severity of CP is declining.
- **On the five-level Gross Motor Function Classification System (GMFCS) scale used to classify functional mobility, 63% fall into groups I-II (unassisted mobility), 11% into group III (require use of mobility equipment e.g. a walker) and 26% into groups IV-V (always require use of a wheelchair for mobility).**

The authors of the ACPR conclude; **“These changes in rates and severity can be attributed to the cumulative impact of numerous advances in the health and care of pregnant women and their babies, better management of high-risk pregnancies, improvements in the neonatal intensive care, and the implementation of public health initiatives to prevent accidents, all underpinned by Australian and international research”.**

<https://cerebralpalsy.org.au/wp-content/uploads/2023/06/2023-ACPR-Report.pdf>

A Winston Churchill Memorial Trust research project carried out by the Founder of Action Cerebral Palsy, Amanda Richardson MBE in 2018, *Identify, Intervene, Impact – An Australian model of best practice for cerebral palsy*, summarised the Australian model of identification, intervention and subsequent impact. <https://actioncp.org/wp->

<content/uploads/REPORT-OF-WINSTON-CHURCHILL-MEMORIAL-FELLOWSHIP-2018.pdf>

**The innovative work of the ACPA and the subsequent fall in severe neuro disability in Australia provides a robust and vital model for research, data collection, prevention and intervention for the UK and Action Cerebral Palsy urges the UK Government to learn from their work.**

*18 March 2024*