



Speech for Round Table Launch of *Variations in Care, Two Year Report.*

Boothroyd Room, House of Commons

February 24th 2020.

Welcome and thank you to all of you here today and who have supported the production of the report. We would particularly like to thank Damian Moore MP, our sponsor today, and our colleagues Emmanuel Hanley-Lloyd and Paul Church at Connect Public Affairs Agency.

After the ups and downs of last year's political landscape, we are delighted to have, at last, the opportunity to launch our Variations in Care Review of provision for infants and children with cerebral palsy, here in Westminster.

Action Cerebral Palsy commissioned a Freedom of Information survey in 2018 and a subsequent report in 2019 to provide a follow-up to our 2016 Report on Variations of Care and as a measure of progress of two significant pieces of work that we hoped would have influenced practice in the field, namely the NICE guidelines on Cerebral Palsy in under 25s: Assessment and Management, and the 2014 Children and Families Act which resulted in the SEND Reforms and Code of Practice.

Both of Action Cerebral Palsy's surveys and reports were driven by a need to provide evidence and highlight the plight of families affected by cerebral palsy who continue to suffer from a postcode lottery of arbitrary and incoherent care pathways. Unfortunately, based on the responses provided, there appears to have been limited improvement in the two years between the reports.

As we all know, there is robust research evidence for the need for prompt identification and evidence-based intensive intervention for infants with, or at risk of cerebral palsy and yet, despite clear guidance on the pathways required in the NICE Quality Standards, there continues to be a lack of urgency in referral for assessment. Only 22 Trusts were able to provide a timescale for referral with the average of these being 10 weeks, but many citing the standard 18-week referral to treatment time. Four and a half months is a very

long wait for an infant with a potential neurological disorder and for their very anxious parents.

We were also very concerned about the apparent lack of formal pathways provided by NHS Trusts for infants and children with cerebral palsy. The majority of Trusts who responded to the survey did not have a formal care pathway and there is evidence that pathways offered are based on what provision is available locally, rather than on what is required to meet the child's specific needs and that, therefore, intervention is resource led rather than child led.

Where pathways do exist, they appear to revolve around access to physiotherapy and whilst this is, of course, extremely important, it is not sufficient in isolation to meet the full developmental needs of an infant or child with cerebral palsy, which, as a neurological condition primarily affecting movement and postural tone, will also have an associated impact on the acquisition of sensory, cognitive and communication skills and on nutrition and general health.

For the very young child, time is of the essence as a result of the optimal neuroplasticity (the way neural pathways and synapses develop and interconnect) of early childhood, and for a neurologically impaired child with CP, intensive, evidence-based intervention across the developmental spectrum is absolutely vital.

This is why better knowledge of the indicators and signs of cerebral palsy (the "red flags") in primary health practitioners such as health visitors and GPs is needed and why a greater sense of urgency is required in the timescales for referral for assessment and subsequent intensive intervention.

Not only is early identification and intervention vital for the child and their family, it is also the most cost-effective practice in the longer term. Rather than wasting valuable resources and money by continuing with disparate models of delivery which are inadequate and often clinically ineffective, local and regional services should work hard to implement specific care pathways as identified in the NICE Guidelines and Quality Standards. The implementation of sustainable and effective pathways will require greater collaborative working and stronger networks between NHS Trusts, community children's paediatric services and local authorities, but will ultimately result in a more streamlined,

transparent and effective service which has the trust of families to make a lasting difference to the well-being and life chances of their children.

The good news is that since the Freedom of Information survey was completed, important work has been done as part of a CQUIN (Commissioning for Quality and Innovation) project led by Dr Charlie Fairhurst, to develop regional networks for movement disorder interventions which will work together to organise care pathways with their wider networks and to minimise duplication of services. These networks will support an interdisciplinary and integrated approach to movement therapy and ensure that pathways and protocols provided across the regions reflect best possible practice.

Whilst this initiative currently focuses on management of muscle tone and musculo-skeletal deformity, the model lends itself to the management and intervention for the associated developmental challenges of cerebral palsy such as communication, sensory impairment, nutrition, sleep and mental wellbeing.

This is an important step forward towards nationwide standard pathways of care for people with cerebral palsy and we call on all those who are able, whether working at strategic or commissioning level, to support these initiatives.

Moving on to Special Educational Needs provision for children with CP, we were concerned that there appears to be a continuing lack of available data from local authorities on how many children have cerebral palsy within their authority – only 5% were able to give a figure for the number of children who have CP listed on their Education, Health and Care Plan. Why is this? I suggest that without a clear diagnosis or description of the condition, it is easier for local authorities to be less specific about the exact nature of provision that is required to support the child both physically and cognitively and that therefore children risk being “short changed” in the level and type of support and intervention they need to thrive.

Local authorities were able to point to the provision of physical therapies for children with cerebral palsy, but there continues to be a shortage of speech and language therapists. There is a recognised shortage of paediatric therapists available to work with children with special educational needs and disabilities across the regions and this has been highlighted in the recent SEND Review. Once again, this leads to therapy provision being resource led rather than child

led and, until this is addressed, children with CP will continue to lack the level of intensive and targeted therapy they require to thrive.

The lack of available paediatric therapy is exacerbated by poor training for education professionals in cerebral palsy. Some authorities, for example, Gloucestershire and Swindon, replied that they *do* provide training and support for teaching professionals, but they appear to be in a minority. Whilst their physical challenges will usually be obvious, children with CP will often have “hidden” challenges to their learning and participation linked to difficulties with sensory processing, fatigue, communication and emotional regulation. These all require skilled and sensitive intervention from educational professionals, without which the child will quickly fall behind or lose confidence in school and, in some cases, develop mental health problems. Mental health is an issue which we all know is growing and is of enormous concern to families and professionals who confront the fall-out of poor mental health in children and young people on a daily basis.

Following the SEND Reforms, the Local Authority run Local Offer was designed to provide on-line details of organisations which families can approach to provide support for their child’s special educational needs and disability. We were concerned that only 3 of the 151 local authorities contacted were able to name services included in their local offer which specifically cater for children with cerebral palsy. Others indicated that they provide information about inclusive groups that would be suitable for children with physical disabilities as a whole. Whilst this is welcome, many parents want to use the Local Offer to find support and advice for their child’s specific disability and with cerebral palsy being the most prevalent physical disability of childhood, it is worrying that there appears to be a lack of condition specific information and resources included in Local Offers.

The snapshot provided by the survey of the varying levels of local authority awareness of children with cerebral palsy and the service they provide for them is mirrored by the experience of the many families across the UK who struggle to obtain a fit for purpose Education, Health and Care Plan for their child. We will hear in a moment, from a mother about her experience, but I have received too many testimonies from parents of children with cerebral palsy who have had to endure appalling frustrations and timescales to obtain an EHCP plan which is seen as the “passport” to support, but is often, due to the bureaucratic mess and inconsistency of staffing within some local

authorities, incorrect, out of date and therefore unfit for purpose. One parent said, “we have been fighting for two and a half years and we still don’t have a final version that is correct.” What a waste of time, money, resources and worst of all, vital months or years of a young child’s life at a time when they should be receiving all the help they need.

Where statutory agencies struggle to meet needs, it is often the private and voluntary sector who pick up children with, or at risk of, cerebral palsy and provide the essential early intervention they need free of charge or highly subsidised. As my colleague, Pilar Cloud says, these services fill the gaps in NHS and LA provision and, because they do so regularly, have a profound and positive impact on these children and their development, yet are ineligible for any statutory funding. Why can’t the allocation of statutory funding be more nimble and flexible so as to enable providers who are ready and willing, to offer vital high-quality early intervention where this can’t be provided by statutory agencies?

Whilst there is still much to do to improve pathways and provision for children with cerebral palsy, we would like to take this opportunity to applaud those Trusts and Authorities which are doing their best to provide a good service for children with cerebral palsy, for example, by having an urgent referral to treatment timescale and creating formal pathways for care. Where possible, we have tried to identify these in the report. Of the devolved nations, Scotland stands out as having some of the most embedded pathways of care for children with cerebral palsy and a higher level of specialist professionals. Whilst of course Scotland has a much less dense population than the rest of the UK, the other UK regions could learn from Scotland’s better practice in this area.

In conclusion, I would like to thank you once again for your interest in the issues raised in our report and to ask you to help us as advocates for children with cerebral palsy and their families.

How can you do this? Firstly, if you are an MP, would you ask a Question in the House for us, or write a letter to your local Health Trusts, CCG and local authority to raise awareness of the issues discussed today? (We can help you with this). If you are **not** an MP, would you write to your constituency MP to request that they contact their local services about the quality of provision they make available for children with cerebral palsy?

We are calling for people to spread the word about Action Cerebral Palsy's work and the key "asks" we made in our recent manifesto flyer namely;

- 🎯 Implementing **best practice pathways** of care as standard throughout the UK and supporting the development of regional multi-disciplinary centres of excellence for infants and children with, or at risk of, neuro-developmental conditions such as cerebral palsy;
- 🎯 Better training for education and health practitioners to ensure they are equipped with **specific knowledge** about cerebral palsy to ensure earlier referral, diagnosis, and high-quality intervention;
- 🎯 Develop a **UK Cerebral Palsy Register** by improving data collection systems in order to provide robust information for planning and research purposes.

Now is a time of national change and we need to grasp the chance to make changes which will improve the lives of some of the most vulnerable children and young people in our society.

We call on you to join us in this task.

Thank you.