

MINUTES
Education, Health and Care Plans

APPG on Cerebral Palsy meeting, 25 May 2021

Chairs: Mary Kelly Foy MP, Co-Chair of the APPG on Cerebral Palsy and Paul Maynard, Co-Chair of the APPG on Cerebral Palsy

Parliamentarians in attendance:

- Tulip Siddiq MP
- Office of the Rt Hon Sir George Howarth MP
- Baroness Fraser of Craigmaddie
- Office of Marion Fellows MP
- Office of Ian Mearns MP
- Lord Watson of Invergowrie
- Office of Thangam Debbonaire MP
- Paul Girvan MP
- Office of Michael Tomlinson MP
- Greg Smith MP
- Office of Dr Lisa Cameron MP

Minutes

Mary Kelly Foy MP welcomed everyone as the Co-Chair of the APPG on Cerebral Palsy. She introduced the agenda for the meeting and spoke about the progress of the APPG since the last meeting, including an Early Day Motion, cross-party support, and written parliamentary questions from the APPG's vice-chairs. Mary went on say that children with cerebral palsy can be excluded because they do not get the learning support they need, and that the session would consider the impact of cerebral palsy as a lifelong condition and ECHPs, which were introduced in 2014.

Paul Maynard MP added some opening remarks as Co-Chair of the APPG on Cerebral Palsy. He spoke about what further needed to be done around education and cerebral palsy, and educating those with cerebral palsy on how to deal with and understand their condition.

Paul handed over to **Amanda Richardson, Chief Executive of Action Cerebral Palsy** for her opening remarks. Amanda said she believed we were still far from having a system fit for purpose for children with cerebral palsy. Amanda said it was time to speak about cerebral palsy as a specific palsy, as their needs were often subsumed into a generic debate on disability. Amanda gave a brief background on what cerebral palsy is, a group of motor disorders, and said there are around 30,000 children and young people living with it in the UK. Amanda said it is the most prevalent physical disability in childhood. She said the condition can have a significant impact on a person's opportunities and quality of life. She said it primarily affects motor function but also encompasses a number of neurological functions which affect all aspects of development in a growing child. She said it requires a novel approach, bridging health and education.

Amanda said that the way cerebral palsy affects a child will be unique, but it could include impact on sense, touch, balance, taste, and coordination, which could lead to hypo- or hyper sensitivity; abnormalities of tone; either been stiff or floppy, rigid, or a fluctuation between these states; delayed writing and balanced reactions; short and long memory deficits; and visual, spatial, and navigational awareness problems. These will impact on all aspects of cognition, including language

and communication difficulties. Amanda listed some of the complex issues children with cerebral palsy and their families face in ensuring their ECHPs truly reflect the breadth of those needs. In regards to ECHPs, Amanda said the plans need to reflect in detail the level of children's needs, regardless of the type of school a child attends, with the overall aim being to reduce barriers to the child's learning and participation, and to optimise their wellbeing and their potential in their future life. All too often, Amanda said there is a lack of joined up approach to teaching and therapeutic and medical intervention, which fails to recognise the interrelationship and interdependency of their physical and learning needs, and that there is a lack of consistency and continuity in the treatment.

Amanda said it is pointless and spurious to try to argue that or communication trunk control are any less a part of learning for a child with cerebral palsy than being literate or numerate. Amanda said she looked forward to hearing the evidence from a range of experts and stakeholders.

Paul thanked Amanda and introduced the next speaker, **Tulip Siddiq MP, Shadow Minister for Children and Early Years**. Tulip thanked the secretariat for organising the APPG and for apologising for needing to leave after she spoke. Tulip said she had done a lot of work on ECHPs as a Shadow Minister, as a MP for Hampstead and Kilburn, and as a former councillor in Camden. Tulip said the deep systemic problems with ECHPs puts children and their families through much difficulties. Tulip said far too many children with SEND can't get the support they need, or spend so long waiting for it that there is a substantial negative impact on their lives, which can lead to isolation, and really hamper their life chances. Tulip said it's the severe delays, poor communication, and lack of accountability at the moment that is common, and a recent local government ombudsman report found that the volume of ECHP complaints increased by 45% between 2016-17 and 2018-19, and that nearly 90% of investigations into these were upheld, which indicates a systemic lack of compliance to the rules from those delivering this support.

Tulip said the situation has worsened in the pandemic, in the height of the lockdown only 16% of children were getting all of the support set out in the ECHP and 21% of parents said their children weren't getting any of the support set out in their plan, which Tulip called dismal. Tulip said the pandemic has increased the backlog of ECHP assessments. Tulip said children with cerebral palsy must get quick assessments, and then the support they are legally entitled to without parents spending all their time lobbying for it. There also must be more support for those transitioning to adult support services, which Tulip said are often inadequate or disconnected. Tulip commended the APPG for making the case for joined up working across Government and external bodies, specific training for professionals engaging with families, early intervention, uniform minimum standards across health authorities and much more. Tulip said she thinks there is fundamental change needed and the SEND review is an opportunity for this.

Tulip said she hopes the Government will take the advice and transform the lives of children with cerebral palsy and their families. Tulip said she will be scrutinising any attempt to downgrade the legal duties on SEND provision, and she there needed to be an upgrade on children's rights, not a downgrade. Tulip said she will be holding the Government to account and focussing a lot on the SEND review. Tulip said people should email her if they wanted to discuss the SEND review as she was having regular meetings with Minister Vicky Ford. Tulip said she would put her details in the chat for people to get in touch.

Mary raised a question from that chat, asking if there should be a Cabinet level minister for children and young people to ensure cross-departmental issues like ECHPs are coordinated and championed appropriately. Tulip said she didn't think it was a silver bullet but that schools do take up a lot of time in the brief so more attention on children and young people's services could be good. Tulip said she didn't want a Cabinet Minister appointed but then for the Government to do nothing else and there be no further change. Tulip said cross-departmental work does happen effectively as long as you have effective ministers determined to get things done.

Paul introduced the next speaker, **Dr Sarah Crombie, Clinical Specialist and Lead Physiotherapist at Chailey Clinical Services**. Sarah made apologies for her colleague, Dr Sarah Gardner being unable to attend.

Sarah said she'd be speaking from the therapy perspective on EHCPs. Sarah introduced Chailey Clinical Services (CCS) a community based, tertiary level centre offering specialist rehabilitation and clinical care. Sarah spoke about how an EHCP is written and that it was the author's knowledge and skill that made a difference in the end to the child. Sarah said there is no standardised training for professionals in how to write EHCPs and that there was a wide range of content and quality in EHCPs across local authorities.

Sarah said it's important to identify very clearly a child's needs including environmental needs – so what school environment they need, what specialist equipment they might need, the maintenance and storage of that equipment, what skills and training school staff need to manage the child's therapy needs as well as the equipment, and Sarah said this often isn't written clearly in EHCPs. Sarah said EHCPs have to be specific as they are a legal document but this doesn't offer the flexibility a child might need.

Sarah said how a school implements an EHCP can be really variable depending on resources, attitudes toward risk and disability, and this can impact on a child's development and ability to participate and join in in that context. Sarah said it's how the school interprets the EHCP, so it might be siloed rather than treated as a whole part of the curriculum. Sarah said a child may need to stand in a standing frame for 3 x 30 minutes a week and a school may withdraw a child from class to do that, or when a teaching assistant is free, or when it fits in with a class; another school might try and fit it in with an activity with other children where they are standing so the child with cerebral palsy doesn't miss out.

Sarah gave some best practice examples of how EHCPs can be delivered in schools such as integrating them into the child's day, and that outcomes should impact on learning, development and participation in school. Sarah finished off by highlighting the importance of staff training.

Mary introduced **Dr Helen Hunt, a Trustee of Action Cerebral Palsy and the parent of Wilf who has cerebral palsy**. Helen spoke about Wilf's condition and childhood, and that one of the main problems is that education provision was often decided not by unique physical health and educational needs but by the resources available to the local authority and often there is only one special needs school. Helen said if there is no early year's provision that specialises in children with cerebral palsy, like PACE and the Rainbow Centre, then families are at the mercy of health professionals in their area to point them in the right direction, but they are often told not to recommend other places offering this specialist care.

Helen said the assessments were geared towards a pre-determined outcome that Wilf would attend the local special school and there was no other option presented or considered. Helen said these schools often are the default schools for children with the most severe SAD and challenging behaviour and that combining these two sets of pupils do not work well. Helen said Wilf cannot stand independently, cannot talk, and has a severe learning difficulty. Helen outlined her experience of Wilf's assessment, which lasted about ten minutes with observation from afar.

Helen said there was no real understanding of Wilf's specific needs as a cerebral palsy child and that the assessments provided by physio and occupational therapy showed they had not fully grasped Wilf's needs, and the input was loose, non-committal and generally lacking. Helen said it was assumed the school would meet Wilf's needs when in fact the school did not have the resources to do so. Helen said Wilf made very little progress in his first year at school and the

“failings of the EHCP assessment process became horribly apparent”. Helen said Wilf’s EHCP was months late in arriving and was “shoddily put together” by a SEND team who had little idea about the needs of cerebral palsy children.

Helen said the EHCP was “barely worth the paper it was written on” and gave the local authority all the wiggle room it needed to claim it was meeting the statutory obligations to meet Wilf’s educational needs. Helen said the EHCP itself is “structurally flawed”, splitting health and therapy needs from education, which can make it clear who is responsible for what but makes describing input and collaborative working between health and educational professionals impossible to describe when for a cerebral palsy child therapy input is an integral part of educational need. Helen said she recognised a conflict of interest between in the local authority allowing NHS children therapy teams to contribute to EHCP assessments when budgetary and other departmental constraints inform the level of service the authority is able to provide to the school before full consideration of the needs of the child.

Helen said that in her local authority few professionals grasped the specific needs of a child with cerebral palsy. Helen said they often had no idea what conductive education was but would advise and recommend about suitable provisions for Wilf and others like him. Helen said that given the resources are so tight, health and education authorities are incentivised to be unambitious for every child. Helen said this goes against the SEND code of practice and that Wilf was failed by an education provision that was too generic in its approach and lacked the specificity for cerebral palsy. Helen said at the heart of this is a broken, compartmentalised system that is not functioning as a whole to address the holistic needs of children with cerebral palsy. Helen said she now lives part time in a caravan 120 miles from home so Wilf can attend a special needs school and really enjoy life.

Helen said the one positive experience she can draw on is when the Head of Early Years at Wilf’s current school took on the task to redraw his EHCP with the help of therapists who understood Wilf’s needs formulating it into a prescriptive plan to protect Wilf’s access to appropriate and effective provision. Helen said it’s only when you have professionals like this supporting your child that your child’s voice can be truly heard through this process. Helen said it is still not enough that the local authority has only made a commitment to funding Wilf at his new school for one more year while they explore appropriate provision in the locality, even though it does not exist. Helen said that was after support from Wilf’s professionals. Helen said she is left in limbo for what plans she can and cannot make. Helen said the key changes she would like to see are: for the EHCP assessment process to be more independent as the LA and health authorities are effectively marking their own homework by having their own staff provide assessment and recommendations for need that their departments provide; assessments need to be provided by specialists in cerebral palsy who have experience of the range of services available; lastly, robust independent support is needed for parents in this process, and legal support and advocacy should be provided to parents.

Paul thanked Helen for a powerful contribution and said the EHCPs had turned out not to be the magic wand he’d hoped they might be. He said it had turned out to be a bit of a postcode lottery and that it was needed to understand what improvements could be made and what councils could do. Paul then introduced the next speaker, **Lucy Atherton, senior SEN Lawyer at IPSEA**.

Lucy introduced IPSEA, a national charity offering free, independent legally-based advice, information and support to get the right education for children and young people with all types of SEND. Lucy said they have supported nearly 900 children with cerebral palsy.

Lucy gave the legal background to EHCPs and that families sometimes need to challenge local authority decision making to get the support the child is legally entitled to, and IPSEA provides advice to families in these situations. Lucy explained that these challenges are heard by the SEND Tribunal, a specialist Tribunal which is free to use, is independent of local authorities, and can only

apply the law. Lucy said 95% of appeals result in a decision partly or wholly in favour of the parent, which Lucy said is an extremely telling statistic and that in many cases local authorities rely on parents or young people being unwilling to challenge their decisions.

Lucy said that in complaints brought to the Local Government and Social Care Ombudsman, 87% of complaints about EHCPs were upheld, and that the Local Area SEND Inspection Programme has found that more than half of local areas inspected by Ofsted and the Care Quality Commission have significant weaknesses when it comes to identifying and meeting children's needs. Lucy said these statistics illustrate the poor quality of local authorities' decision-making processes.

Lucy said an approach that was driven by waiting for and responding to crises can end up costing more than addressing a child's needs at an earlier stage, with incalculable costs for the families. Lucy said, despite tight budgets, local authorities still need to be held to account for how they're discharging their legal duties to the families who depend upon them.

Lucy proposed six policy changes:

- For appeals to be allowed on health and social care matters on a permanent basis.
- Tribunal powers on health and social care should be strengthened so that binding audits can be made, not simply recommendations as is the current case.
- The restoration of all support and SEND provision withdrawn from children during the Covid-19 pandemic.
- No dilution of existing rights and entitlements when the SEND review concludes.
- Sufficient funding to ensure all children with SEND receive the support required to meet their individual needs.
- Introduction of a robust, accountability framework to identify when local authorities are not meeting their statutory duties with serious consequences for unlawful decision making.

Mary thanked Lucy for her contributions. Mary said from her own experience that the issue of having education, health and social care, and who was going to pay for what equipment, that it needed a joined-up approach. Mary then introduced the final speaker, **Claire Smart, Director of Education at The Pace Centre.**

Claire opened by saying there seemed to be a common misconception that cerebral palsy was purely a physical disability or motor impairment. Claire said that it is easy to overlook that a child with cerebral palsy puts information together differently, the quality of the information will be different, and the processing of the information will be slower, so it's important for professionals to understand it's not just about movement but about sensory processing.

Claire said the EHCPs should, in principle, be a "magic wand" to meet the educational and therapeutic needs of children with cerebral palsy but this system can only meet the needs if the professionals conducting the assessments are trained to an appropriate level on cerebral palsy and are truly independent and unbiased.

Claire said the EHCP is the pivotal gateway for a child with cerebral palsy to access support and specialist provision and it's imperative it's written by unbiased professionals with expert knowledge of cerebral palsy to ensure appropriate school placement. Claire said it was meant to be highly child-centred, with outcomes set to inform provision required to meet the outcomes, which should be used to inform the appropriate placement for the children. Claire said she found Helen's testimony quite emotional and that the experience was all too common.

Claire said there are vast differences in the way EHCPs are written, not just across local authorities, but within SEND teams. Claire said she's experienced staff shortages leading to temporary SEND

officers being drafted in without the appropriate training in cerebral palsy which can result in the EHCP not being a true reflection of the child's needs.

Claire said it has been her experience for expert clinical recommendations to be totally disregarded or excluded, with the SEN officer or EHCP coordinator writing the EHCP seeming to choose to omit clinical assessment informed advice which can result in a family challenging the Local Education Authority to get these recommendations included, which can be very expensive.

Claire said needs of cerebral palsy do not fit neatly into the themes of an EHCP. Education and therapy seem to get separated and considered in isolation, disregarding the fact that children with cerebral palsy are a lot more cognitively able than their bodies are able to show. Claire gave an example of a young person at PACE with cerebral palsy whose therapeutic provision had been separated from their education provision, suggesting the therapy was not a need to access the education, which simply isn't true.

Claire said children with cerebral palsy are entitled to the provision which meets their complex needs, and their curriculum needs to span way beyond the academic, reaching to sensory processing and regulation, communication, motor control, play, and activities for daily living. These areas of living, Claire said, happen organically and naturally for able-bodied children, but it is part of an appropriate, integrated curriculum for a child with cerebral palsy.

Claire said that to meet this aforementioned curriculum requires a combined clinical and educational expertise of a multi-disciplinary team to fully address the broad and complex needs that go far beyond a physical disability from the outside. Claire said it must avoid therapy been bolted on as a one-size-fits-all activity and must be woven through all aspects of the school day.

Claire outlined the risks of children with cerebral palsy not accessing this provision including being underestimated in terms of their abilities, becoming disengaged from their learning, and becoming passive both in their attention and physical activity which could increase muscle atrophy.

Claire said to avoid the risks outlined above, families must summon the strength and resources to battle in a system where their child's needs are seemingly underestimated and misunderstood. Claire said the struggle is endured on top of the grief and trauma families can experience when caring for a child with a complex neuro-disability. Claire said the Pace Centre invests a lot of time in relationships and communication with the LEA SEND teams, as well as supporting families in navigating a system that seemingly tests and challenges them as opposed to placing them at the heart of the process as promised in the SEND reforms. Claire said the Pace Centre will continue to offer SEND offices within PACE LEAs training on cerebral palsy free of charge, continue to deliver training and outreach support to schools, and are building a digital platform to offer support.

Claire said there is so much to be done, and outlined three key priorities: increased awareness and expertise about cerebral palsy to inform the EHCPs, which should be written using recommendations from expert and skilled, independent and unbiased professionals; adequate funding for LEA SEND teams to support appropriate placements for children with cerebral palsy; and universal access to appropriate and integrated curriculum provision delivered by multi-disciplinary teams for children with cerebral palsy. Claire said she believes it's our shared responsibility to ensure the quality and appropriateness of EHCPs and resulting provision so young people can realise their full potential.

Mary thanked Claire and opened the floor for questions.

Amanda Richardson said the issue of expertise had come up a lot in the session and that each child deserves to be assessed by someone who really understands how they communicate, the impact of the assessment experience on the child's sensory system, and on their behaviour, and that it is easy to get a false picture of the child's abilities if the assessment isn't done sensitively.

Amanda raised concerns around the validity of some of the assessments informing EHCPs and asked how it can be ensured that individuals have that depth of knowledge required.

Sue Dorrington said she believed we needed specialist clinics with multi-disciplinary teams with people qualified to holistically assess cerebral palsy, perhaps a nationally accredited clinic, as parents face scanty LA assessments where cognitive assessments are cherry-picked because of time limitations. Wealthier parents might seek an independent assessment but LAs say they won't take account of independent assessments, as schools also say, which adds to delays and confusion and stress. Sue went on to speak about the action of an EHCMA, and that there are delays because education settings haven't doesn't the evidencing of the support they've put in place and the impact of that support, so the EHCMA's are blocked at the first hurdle, so the families are failed because the LA can't take the EHCMA on.

Mary referred to some comments from attendees in the chat that those parents who had capacity to navigate the system so could end up pushing for the best provision for their child, and conversely families who didn't have time or experience ended up with lesser provision. Mary cited her own personal experience, saying she thought she could navigate the system but didn't know what to ask for, or what was on offer, so people do need that expert and suggestions. Mary said only one school had been available for her daughter, so it was difficult to know the quality when there was nothing to compare it to.

Paul said the issue of navigating the system was an interesting dilemma for policymakers, and it was a question of making a better system or offering more support to those who find it difficult to navigate, and which policymakers should focus on first, as making the perfect system would take longer but then they weren't supporting those who are struggling.

Sue responded saying key to equality was families being able to self-advocate and being able to advocate equally, regardless of background, and that SEND services across the country are struggling to provide that support for families, even though they are free at source for all families, and it's becoming a national problem that needs to be taken to central government. Sue raised the issue that families from a lower socio-economic background are going to struggle more because they can't access independent or private advocacy.

Helen said she had raised the above issue in her speech in the Parliamentary report for Action Cerebral Palsy and that as a doctor, an educated woman – and Wilf's dad being a journalist – they have a strong voice for Wilf, and a combined voice that offers strength, but a lot of families would not know how to navigate the system. Helen said it has taken her a lot of time, even with her skills, and that parents are exhausted with caring for children and that there are so many care needs that need to be covered, and access to social care and respite is a whole other topic that needs to be covered. Helen said families can't rely on professionals most of the time to have the right expertise and experience to do the fighting for them. Helen said it comes down to being purely exhausted and takes a lot of time and energy to navigate this system.

Sue referred to Sarah's point around integration into the whole day curriculum and said it can work very well in certain contexts and settings, and that it needs to be done in early years, primary and special settings, but in the mainstream setting it is very difficult to integrate therapy into the whole day curriculum, and therapy did become a stand alone session out of the whole curriculum and it is about bringing the child into the centre of the discussion and what they think. Sue said it was vital to bring the voice of the child into it, take account of the setting, and that there was no one size fits all approach. Sue said a whole day curriculum approach had helped her son be compliant with his curriculum into adulthood and had taken real responsibility and accountability to carry that integration through his life, but it was important to find a fit for the child and the setting.

Mary thanked all attendees and said that all the information from the meeting would inform the next APPG report and reminded attendees of the call for evidence. Mary and Paul both thanked the speakers and secretariat and closed the meeting.