

Bobath Centre

For Children & Adults with Cerebral Palsy

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The National Bobath Cerebral Palsy Centre's submission to the All-Party Parliamentary Group for Cerebral Palsy for the Call for Evidence regarding Education, Health and Care Plans (EHCPs) for children with Cerebral Palsy and the Best Practices in Teaching and Learning for children with Cerebral Palsy– June 2021

About The National Bobath Cerebral Palsy Centre

The Bobath Centre (The National Bobath Cerebral Palsy Centre) was founded in 1948 and is a provider of specialist therapeutic services to babies, children and adults with Cerebral Palsy (CP). Our charity is the original home of the Bobath approach to therapy for CP, which is a holistic, multi-disciplinary approach to treatment that supports people with CP and other neurological conditions across the lifespan. We are a leading provider of training for therapists to NHS and private therapists, health and social care professionals and others with an interest in providing treatment and care to people with CP. Our therapy services for children are delivered by Bobath Physiotherapists, Speech & Language therapists and Occupational therapists at our specialist centre in Watford. In addition to in-person therapy, we also support families of children with CP through online consultations and through our "Bobaby" service, which is an on-line playgroup for babies (0 to 2.5 years) with developmental delay.

With some financial support through fundraising, The Bobath Centre is able to offer sessions of Early Intervention therapy to some babies with developmental delay where CP is suspected, free of charge. Specialist CP therapy offered by the Bobath Centre provides the best start for children with CP and should continue throughout their lifetime. For instance, our therapy supports young children to prepare to attend preschool and primary school. Through liaison with schools, our therapists can support schools and signpost to other organisations to ensure the individual needs of children with CP are met.

Response

The Bobath Centre strongly supports the rights of children with CP to have equal access to the national curriculum and opportunities to thrive educationally, on the basis of the best therapy provision and support possible.

Voice of the Child and Role of Parents

Ensuring the voice of the child or young person with CP can be heard should facilitate the inclusion of children and their families in the decision-making process about their education and care. It is our view that parents of children with CP are the best advocates for their child. The ability of parents to play a supportive role in ensuring EHCPs identify their child's needs and provide appropriate provision is enhanced by the supply of timely and effective information and guidance. Parents of babies and children with developmental delay require access to timely information about their child's medical condition, as well as information about how they can learn to navigate a difficult and challenging system with professionals from health and social care, Local Authorities and Education. Parents report difficulty navigating funding for health within education settings. We have been advised some local schools have deterred parents from asking for some equipment or services, citing that their Council won't have the associated budget. In this way schools can become gatekeepers and unwittingly limit the provision for the child by reducing parents' expectations. Funding routes are difficult to navigate, with very little crossover or understanding about what is actually required to implement an EHCP that details children's needs, above what can be provided by local teams. Therefore, parents need information and guidance about what to ask for, including not just what provision is available locally to them by their Council, but rather what provision meets their child's needs, in order to deliver the best long-term outcomes for their child and their family, including their transition into adulthood.

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Characteristics of CP that affect learning

Cerebral Palsy affects control over movement, balance, and posture, and the associated lack of movement limits sensory learning from birth. Premature babies have higher incidence of specific learning disabilities and ADHD, even when their physical deficit is mild. Communication needs are not routinely looked at until after 2 years of age and children start school without definitive communication and learning strategies in place, so they join Reception class ill-prepared. There may be associated problems of vision and hearing, as well as less obvious problems, such as perceptual disorders. Time-off for medical appointments and invasive surgery and recovery may impact their learning.

Their physical needs include the use of equipment, which if not available will hamper their learning. Incidence of anxiety can be higher in school age children with CP, particularly if they are non-mobile and they may need to be hoisted to leave the classroom several times per day in mainstream schools. Additionally, problems of posture and movement increase with emotion and the demand of the activity at school will impact their concentration levels and ability to absorb information, putting the child at a disadvantage to develop academically.

The skill sets, knowledge and attitudes for carrying out EHCP Assessments

Our view is that it is crucial that parents have access to the appropriate professionals when drawing up their child's EHCP, and that the child with CP is assessed in-person by those professionals. Vitally important is that the professionals have skill sets and knowledge informed by CP awareness. The skill sets and knowledge of professionals must take into account the changing nature of CP as children age, so professionals must be appropriately experienced in understanding the needs of children, teenagers and young people with CP up to 25 years. Attitudes for assessments should include the desire for ensuring the very best outcomes will be delivered, irrespective of the limitations of local provision for children with CP and the limitations of budgetary concerns within the Local Authority. The attitudes professionals must adopt should be to work in partnership with each other and with parents, and to put the needs of the child before that of their Local Authority's budget.

EHCP proformas

Parents have advised us that EHCP proformas are not always suitably or sufficiently detailed, so that the needs of their child are not always met, in terms of the provision allocated in schools. Greater specificity and detail by professionals would ensure the EHC plans are followed more stringently and that they support Local Authorities to deliver services that meet the needs of children with CP in schools.

Collaborative Working and Local Authorities

Children with CP often have complex needs that alter over time and parents report difficulty navigating funding each time. It is incumbent on Local Authorities to ensure relevant CP-informed professionals from multiple disciplines, including therapy, fully assess children's needs and engage in working collaboratively in each child's best interests. This is the very best way to ensure that children with CP can access the specialist equipment and expertise they need, such as correct seating, standing frames, audio equipment and other equipment that will support the child's education and social development at school. Impact assessments should be undertaken if EHC plans are not implemented appropriately.

Current capacity of local NHS paediatric services

We understand that many local NHS paediatric services are stretched and may not have specific skill sets, knowledge and attitudes for carrying out EHCP Assessments to serve the needs of children with CP. Provision in EHC plans should not be limited to Local Authority services alone and should be based on individual children's needs, including their therapy needs. Capacity can be increased through partnership working with voluntary sector organisations, such as The Bobath Centre, a centre of excellence in the provision of therapy for CP. This will support current local capacity, with objective, expert advice delivered in a timely manner.

Role of therapies

Children with CP require support to maintain progress and their development needs alter continually. Specialist therapy is required, including physiotherapy, speech and language therapy, occupational therapy and psychotherapy, and therapists should work closely with schools to advise on each child's specific needs.

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Therapists should advise schools not just on each child's requirements, but should also recommend equipment (hoists, walking frames, chairs, side-line boards for 24-hour postural management, communication aids and environmental control systems). School staff that comprise the support team for each child should be informed of their individual therapy needs by therapists, who should assess if the school and classroom layout is safe, suitable and optimal, as well as advising on access issues to areas of the school, such as toilets or the library. Therapists may also support parents with guidance about the manner in which therapy should be provided in school and offer additional specialist expert therapy support for children with CP who have complex needs which are not met in school. Offering parental choice in therapy is crucial to ensure the child's changing medical needs are met.

Training and professional development

Community therapists may provide school staff with suggested activities and equipment for children with CP in the school environment. In our experience, school staff do not routinely receive training on carrying out therapy programmes in school and we have experienced confusion in schools about which therapy activities should be conducted by their school staff. Equally, the frequency in which therapy programmes are reviewed and goals are evaluated varies from school to school and child to child. Frequent and regular training from specialist expert therapists is a requirement, to ensure children settle well into school. This is necessary both for a child with CP to be able to continue to thrive based on one-to-one care for their individual and changing needs, as well as for ensuring schools are fully supported and CP-aware.

In our experience the ability of schools to deliver effectively on EHCPs varies enormously and too many pupils do not have access to effective and equal learning opportunities. It is recommended that teachers, practitioners and other education specialists take the Bobath Therapy Assistant's Course to enhance their understanding of CP in children and as a means of understanding how to support the learning, communication and developmental needs of children and young people with CP.

Assistive Technology and Augmentative & Alternative Communication (AAC)


Each ECHP must specify and detail the exact equipment children with CP need, so that the correct technology or AAC can be provided. If there is uncertainty, Local Authorities should take advice from specialist centres in CP, such as The Bobath Centre, who can help with sourcing and supply. Assistive technology and AAC can be very complex and so training should be provided to school staff in the management of the equipment, including developing protocols for the availability, maintenance and insurance of equipment, such as ensuring back-up equipment is available when needed.

Improving transition between key stages and settings

We recognise the current situation that places onus on parents to demand suitable education placements for their children is unfair and stressful to families. As an all-age service provider, The Bobath Centre supports both children and adults with CP and many have reported being let down by the education system. Frequently we hear that schools do not take account of the child's whole needs (e.g. learning, physical and social development) and fail to provide support for employment. Parents have referred to the current provision as "piecemeal". It is recommended that a comprehensive multi-disciplinary review of the child is undertaken before transition between stages and settings. Therapists should be involved in such reviews and continue to work with the child until they are 25 years of age.

We are grateful for the opportunity to submit evidence to the APPG on CP and would be happy to supply further information if that's useful.

Yours sincerely,



Madeleine Cassidy
Chief Executive Officer
National Bobath Cerebral Palsy Centre