



ACTION CEREBRAL PALSY MANIFESTO

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

Following the 2015 Parliamentary Inquiry, resulting in the report, *Enabling Potential - A New Deal for Children with Cerebral Palsy*, we commissioned a 2016 inaugural Freedom of Information report and a subsequent 2018 follow-up report on cerebral palsy provision across the UK. This new report provides evidence of continuing unacceptable levels of variation in the quality of services across the country, with many families suffering from a post code lottery of arbitrary and inadequate provision.

Our survey revealed that:

Only 22
of the 169 NHS Trusts
who responded
provided a timetable
for referral of children
with suspected cerebral
palsy

Only 10%
of NHS Trusts
were able to provide
a formal care pathway
for children and young
people with cerebral
palsy

Only 13
NHS Trusts
responded that they had
adopted the NICE guidelines
on the assessment and
management of cerebral
palsy in under 25s

This unacceptable situation requires the urgent attention of decision makers.

Please help us to support the many children with cerebral palsy and their families across the country by committing to the following in your manifesto:

- ⊙ 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.

We will release our Variations in Care report, which will include nationwide findings and key recommendations, to Parliamentarians, commissioners, academics, education, medical and healthcare professionals in January 2020, following the general election.

On behalf of the thousands of children and families who are affected by the current failure to create, implement and maintain high quality pathways of care, we hope that MPs will use the new Parliamentary session as a chance to hold their Health Trusts, CCGs and Local Authorities to account and improve the lives of some of the most vulnerable children in our society.