Written evidence submitted by Action Cerebral Palsy (PHP0015)

About Action Cerebral Palsy

1.1 Action Cerebral Palsy (ACP) is an independent campaigning organisation working to improve public, professional and political awareness of the issues facing children and young people with cerebral palsy. We aim to represent the best interests of the cerebral palsy community to policy makers and are committed to developing models of best practice at national and local levels.

1.2 Our vision is that every child and young person in the UK with a cerebral palsy is able to access, from birth, the best possible intervention, care, education and support to meet their complex and changing needs. We are committed to raising awareness of the need for early identification and intervention, particularly for those in the “golden period” of age 0-2, where neuroplasticity is high and interventions have the greatest impact.

1.3 In January 2015, Action Cerebral Palsy published a report on the findings of a Parliamentary inquiry on cerebral palsy led by Paul Maynard MP and Mark Hoban MP, entitled ‘Enabling Potential - Achieving a New Deal for Children with Cerebral Palsy.’ The findings were wide ranging and heard from parents/carers, as well as practitioners, from the health and education sector. The recommendations made were informed by the findings and sought to address service improvements on a local and national level.

1.4 This submission highlights that parents of children with cerebral palsy are still encountering difficulties with the diagnosis and referral of their child’s condition, despite the reforms. It argues that should local authorities’ consolidate health visiting and school nursing services into a single service, they should ensure that only early years specialists conduct early years checks. It also stresses the need to prioritise investment in early identification and intervention, in light of budgetary pressures, to enable financial savings in the future.

Delivery of public health functions

2.1 Evidence collected by Action Cerebral Palsy as part of its 2014 parliamentary inquiry found that health visitors (as well as GPs) are not identifying and referring children who are presenting with developmental difficulties which may be a result of cerebral palsy quickly enough. This evidence also suggested that many parents found the process of identification and referral to be very difficult. A survey of almost 250 parents/carers of children with cerebral palsy found that in a fifth of cases, their child was diagnosed aged two or older, with 54% believing that the process of diagnosis did not work as well as it should have (largely due to health visitors and GPs not taking the concerns of parents/carers seriously).

2.2 It is important that health visitors are provided with adequate training and resources to enable them to identify and refer children showing signs of cerebral palsy. Health visitors need investment in training, as well as high quality and clear guidance – from clinical commissioning groups (CCGs) and NICE, as well as local authorities – to ensure that they are best equipped to do their jobs. ACP’s survey found that 28% of parents/carers did not believe that health professionals took their concerns seriously, with complaints that some were adopting a “wait and see approach” – something that was verified by practitioners who gave oral evidence as part of the inquiry.

2.3 The inquiry also identified that parents believed NHS professionals should have more awareness of cerebral palsy and the follow-up options available. Some parents complained that NHS professionals were either unaware of existing specialist educational/therapy centres in the voluntary and independent sector or reluctant to refer families to them.
Public health workforce

3.1 Local authorities that have combined their health visiting and school nursing services into a single 0-19 Healthy Child Programme Service (HCPS) must take additional steps to ensure that practitioners delivering the service are appropriately trained to identify symptoms of cerebral palsy in children aged 0-2. Local authorities should enable practitioners who have expertise in identifying conditions like cerebral palsy in early years to focus on 0-2 health checks without being required to attend to older children. Moreover, practitioners who normally interact with older children and do not have specialist expertise and experience with those aged 0-2 should not be required to attend to children of this age group.

Public health spending

4.1 Local authorities should recognise that prioritising investment in early identification and early intervention will yield future financial savings. Children with cerebral palsy who receive intensive intervention early on, when the level of neuroplasticity is at its highest and the brain most responsive, are more likely to have a higher level of independence. This means that they are less likely to require costly interventions later in life, and will also have a higher level of physical and emotional health and wellbeing, lower levels of stress, and improved social development – all of which are required to live a healthy and productive life.

Moving forward: recommended policy changes

5.1 Local authorities should work with Public Health England and Health Education England, as well as bodies like the Institute for Health Visiting, to ensure that health visitors and 0-19 HCPS practitioners have the correct training to identify children with cerebral palsy.

5.2 Local authorities should work with CCGs and partners like NICE to ensure that care pathways are in place, enabling health visitors and 0-19 HCPS to refer children with cerebral palsy on for further treatment.

5.3 Local authorities should consider investing in early identification and specialist intensive intervention as this will result in financial savings elsewhere in the future, as children who receive such support earlier have a better chance of being more independent than those who do not.

14 December 2015