Written evidence submitted by Action Cerebral Palsy (CSR0022)

About Action Cerebral Palsy

1.1 Action Cerebral Palsy (ACP) is a registered charity working to improve public, professional and political awareness of the issues facing children and young people with cerebral palsies. 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 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.

Executive summary

1.4 This submission argues that the Spending Review’s 3.9% reduction in funding for public health services over the next five years – along with the removal of the funding ring-fence after 2017/18 – will negatively impact on the provision of health visitors. This will mean a reduction in the capacity for identifying cerebral palsy early, and a reduction in support for children and their families. This will happen directly due to financial limitations in recruiting and retaining existing health visitors, and indirectly through merging health visiting and school nursing services into a significantly broader single zero to 19 service. This will also mean that additional pressures will be placed on general practice in absence of health visitors – an area that the Five Year Forward View that NHS England is adamant that it wanted to avoid.

1.5 This submission highlights that the long-term costs associated with the failure to intervene early will result in long-term costs to the NHS, as well as education and social care services, a significant amount that could be prevented.

1.6 This submission also calls for clarification on how the Care Quality Commission will meet its requirements, including extra functions to jointly inspect health systems on their provision of special educational needs and disability provision with Ofsted.

Reductions to the public health budget

2.1 According to the Spending Review, the public health system will be required to make “average real-term savings of 3.9% over the next five years”, with the public health grant reduced by £200 million – or 6.2% for each local authority – from 2016 onwards. The provisions to ring-fence the funding will expire after 2017/2018, likely leading to further cuts. The commissioning of health visiting
services became the responsibility of local authorities in October 2015, following a transfer from Public Health England.

2.2 The budgetary reductions will mean that there will be fewer funds available to recruit and retain health visitors, which play a key role in identifying cerebral palsy and providing ongoing support to children and their families. The effect of this will be a reduction in service provision, including slower referral times, leading to greater long-term costs for the NHS, education services and social care. It will also lead to the burden of identification falling on GPs – something that they do not have the capacity to accommodate. The Five Year Forward View noted that “immediate steps” are required to “stabilise general practice”. These developments are not conducive to helping general practice achieve stability.

2.3 Early identification yields future financial savings, which helps support the Five Year Forward View’s financial objectives. 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.

2.4 Action Cerebral Palsy’s 2014 parliamentary inquiry showed that “there was strong consensus among the practitioners giving evidence to the inquiry that GPs and health visitors are critical in helping to ensure rapid referral for an early assessment”. However, the inquiry also found that a further investment in health visitor training would be beneficial, as a survey of almost 250 parents/carers conducted as part of the inquiry found that in a fifth of cases, their child was diagnosed aged two or older, 54% believed that the process of diagnosis did not work as well as it should have largely due to health visitors and GPs not being sufficiently equipped to identify cerebral palsy. In addition to identification, this should also include information provision on referral to specialist educational/therapy centres in the voluntary and independent sector – something which local authorities are less likely to be able to take forward if they are stretched for resources.

2.5 A number of local authorities have also already indicated that they will integrate health visiting and school nursing services into a single zero to 19 healthy child programme service, leading to a significant broadening of conditions to be covered at the expense of depth of specialisation. This is largely as a result of a necessity to be as creative as possible with resources. Rather, 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.

Reductions to the Care Quality Commission budget

3.1 The Health Select Committee should clarify with the Department of Health how it expects the Care Quality Commission (CQC) to deliver its duties to inspect health and social care settings despite a 25% budget reduction as part of the Spending Review. We are particularly keen to receive clarification on how the budgetary reduction will impact on the CQC’s capacity to jointly deliver inspections of the provision of special educational needs and disability services in local systems with Ofsted. This is important as ACP found in its parliamentary inquiry that both clinicians and parents
were unsure of service provision in their local areas, which impacted on the ease of therapy that their children could receive.

**Sustainability and transformation plans**

4.1 ACP is keen for local health system leaders – such as heads of CCGs, trusts and health and wellbeing boards – to actively and publicly engage with third sector organisations with high levels of expertise when developing their sustainability and transformation plans. This will allow for best practice to be integrated into service design, as recommended in the Five Year Forward View. These plans are being funded by the partial frontloading of the £8 billion of additional government funding by 2020.

**Moving forward: recommended policy changes**

5.1 ACP recommends that the Health Select Committee should:

- Liaise with the Department of Health and the Treasury to ensure that aspects of public health service delivery, such as health visiting services, are adequately funded. This includes encouraging both departments to work with local authorities to ensure that funding meant for public health services is spent on public health services.
- Seek assurances from the Department of Health, the CQC and Ofsted that the CQC and Ofsted are adequately resourced to carry out planned inspections of local provision for special educational needs and disability services.
- Work with the Department of Health, NHS England and CCGs to ensure that local health system leaders are required to publically engage with stakeholders in an open and transparent manner when developing their sustainability and transformation plans.

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