

iHV Evidence for APPG on cerebral palsy

A. Introduction:

1. The Institute of Health Visiting (iHV) was established as an independent charity and centre of excellence for health visiting in 2012, with the support of the Cabinet Office and Department of Health, to strengthen the quality and consistency of health visiting services for the benefit of all children, families and communities. Our Vision requires health visiting to play its fullest part within an integrated system to reduce health inequalities that arise in childhood and for our children to achieve health outcomes on a par with the best in the world.
2. In this submission, we provide a summary of what we know about the ways that the health visiting service can support the APPG's ambition to improve early identification and intervention for children with cerebral palsy.

B. Summary:

3. Our work in this field of primary prevention and early intervention makes clear the following key points:
 - 3.1 There is indisputable evidence that **the first years of a child's life are the most crucial period of human development**, providing a foundation for health, wellbeing, educational and economic success across the life-course. What happens during this time matters - the effects of early disadvantage are cumulative and associated with health, economic and social inequalities which can pass from one generation to the next in the absence of effective measures to tackle these.
 - 3.2 Failing to intervene early represents a **significant cost to the Treasury**, alongside the personal cost to the child and family associated with widening inequality, which is often cumulative across the life course and can transmit from one generation to the next if not addressed. The estimated lifetime cost for a single 3yr old child who suffers a severe traumatic brain injury is estimated to be £4.89m¹.
 - 3.3 **Inequalities are not inevitable**. However, despite overall improvements in child health, the UK lags behind other countries on many key health outcomes, with health inequalities seen across all indicators.
 - 3.4 We have enough evidence on "what works" to make a difference now. **Early identification of need and vulnerability, with effective early intervention**, play an important role in preventing and mitigating childhood adversities and supporting all children to achieve their potential.
 - 3.5 Health visitors lead the delivery of the Healthy Child Programme and are a highly skilled workforce of Specialist Community Public Health Nurses who are equipped to work in partnership with parents and communities to **address a multitude of key government priorities for children and their families and straddle the Government's three categories of vulnerability** (Clinical; Statutory; and due to wider determinants/ family circumstances).² The universal health visiting service coordinates support and works in partnership with others within an integrated "whole system" approach for the earliest years of life.

¹ Public Health England (2018) Reducing unintentional injuries in and around the home among children under five years https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/696646/Unintentional_injuries_under_fives_in_home.pdf

² Public Health England (2020) No child left behind: a public health informed approach to improving outcomes for vulnerable children. <https://www.gov.uk/government/publications/vulnerability-in-childhood-a-public-health-informed-approach>

- 3.6 The health visiting service provides a **vital “safety net”** for vulnerable babies and young children, identifying those who are easily hidden from sight and lack the protection and lines of accountability that schools provide universally to older children. Having skills to work in partnership with parents and communities to identify and support the physical, emotional and social needs of both children and their parents, reduces fragmentation and the likelihood that vulnerable children will fall through the gaps between services, which is highlighted as a significant risk factor in almost all Serious Case Reviews³.

C. The contribution of health visitors’ to improving outcomes for children with cerebral palsy

4. “Prevention is better than cure”⁴

Whilst many cases of cerebral palsy are not easily preventable, health visitors can play a crucial role in mitigating some of the known risk factors including:

- i. Preconception care- to reduce the prevalence of preterm birth and adverse pregnancy outcomes by supporting women to prepare for a healthy pregnancy in terms of lifestyle factors such as smoking, alcohol and substance misuse, obesity and pregnancy spacing which can be altered by changes in behaviour or, in other words, are modifiable; as well as promoting the early uptake of antenatal care
- ii. Promotion of immunisations and early detection of neonatal risk factors including, brain infections and prolonged neonatal jaundice
- iii. Promotion of accident prevention advice to parents to reduce traumatic brain injury.

5. Early identification:

5.1 All children in England receive 5 mandated health visiting reviews (antenatal, 10-14 days, 6-8 weeks, 9-12 months and 2-2.5 years). Health visitors play a crucial role in the early identification of children with atypical or disordered patterns of development or with significant impairments likely to result in disability. (NOTE: PHE are currently reviewing the schedule of HV contacts in England with a view to increasing the number in line with the other devolved nations; the iHV recommend 3 additional universal contacts at 3-5 weeks, 3 months and 3.5 years, which would increase the opportunity for early detection of children with cerebral palsy).

5.2 Health visitors are often the first point of contact for families who have concerns about the way that their child is developing and are therefore ideally placed to facilitate effective support and provide information about local and national services.

5.3 Identifying and safeguarding the needs of vulnerable children are central to the work of health visitors. This includes: supporting individuals and groups who do not currently experience easy access to services and consequently do not experience the same health outcomes as the rest of the population; and ideally offering additional targeted follow-up to “high-risk” children including those born prematurely who are at particular risk of developmental delay.

6. Early intervention – support for the child and parents

6.1 Early identification of developmental disorders is important to enable prompt diagnosis and tailored interventions⁵, including supporting parents.

6.2 Many parents report that they find the healthcare system complex to navigate and value support adjusting to their role as a “parent of a child with a disability”. The health visitor’s in-

³ NSPCC – national repository of Serious Case Reviews.

https://library.nspcc.org.uk/HeritageScripts/Hapi.dll/search2?&LabelText=Case%20review&searchterm=*&Fields=@&Media=SCR&Bool=AND&

⁴ Prevention is better than cure – Matt Hancock’s speech to IANPHI (2018)

<https://www.gov.uk/government/speeches/prevention-is-better-than-cure-matt-hancocks-speech-to-ianphi>

⁵ Emond A, Law J, (2019) Supporting children with developmental disorders and disabilities IN Emond A (eds) (2019) Health for all children: fifth edition. RCPCH, London.

depth knowledge of local support, referral pathways and relevant benefits can provide an important brokering role to ensure that children with suspected cerebral palsy receive the help that they need. However, in reality there is significant variation in the level of support that health visitors are able to provide which can be curtailed by poorly defined local commissioning specifications and the impact of local cuts to health visiting services. It is therefore crucial that pathways for children with cerebral palsy, indeed all children with SEND, are centrally funded and take a “whole-system approach”, rather than being reliant on regional commissioning models or a NHS only funding stream (health visiting is funded through the 0-5 public health grant to local authorities, although the benefits of a robust health visiting service accrue to the NHS, CCGs and numerous government departments).

6.3 Health visitors are also in a unique position to promote learning in the home environment from antenatal through to school entry, building on the strengths within families and providing support and guidance when required.

6.4 Children from disadvantaged backgrounds are disproportionately represented within the population of children with SEND. In a recent report, the Children’s Commissioner updated the economic case for early intervention at a young age, emphasising that we could do more to help those children who end up in extreme need in later childhood⁶.

7. The current state of health visiting

7.1 **Underinvestment in health visiting is a long-standing concern**, with unwarranted variation on the support that families receive based on where they live due to significant flaws in the way this nationally-funded health visiting service is prioritised and delivered.

7.2 The COVID-19 pandemic imposed an unprecedented public health challenge on an already depleted service following year on year cuts to the public health grant and a **31% reduction in health visitors since 2015**⁷.

7.3 Increasing the health visiting workforce will ensure families receive additional universal and targeted support as recommended by the Health and Social Care Committee⁸. **Councils urgently need funding to reinvest in the preventative services that their local children, young people and families need**, so that we can make sure help is available when it’s first needed – not later down the line when the situation has reached crisis point.

7.4 Government needs to find a way to protect this vital workforce into the long term so that its activities are no-longer at risk from policy changes by subsequent governments. Currently, there are many policies that do not seem to take account of the logic of balancing economic, environmental, health and social outcomes. Too often departments appear to continue to focus on their own specific perspective and remit, “ploughing their own furrow”. This is particularly the case in relation to spending on the early years of a child’s life. Health, education, social care, local services and third sector services all collide in a patchwork of plans and funding programmes that are fragmented at every level of the system and ultimately lead to fragmented support for families. The evidence is clear that investing in the earliest years of life saves money in the long run. **It is precisely because the government is facing a tight fiscal settlement post-COVID that this “investment to save” is needed now, more than ever.**

⁶ Children’s Commissioner (2020) Best beginnings in the early years. <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2020/07/cco-best-beginnings-in-the-early-years.pdf>

⁷ Latest published data on the health visiting workforce indicates 7,768WTE. (6,621 WTE recorded on NHS HV workforce data August 2020; 1,147 WTE recorded on Independent Healthcare Provider workforce statistics published Feb 2020; Percentage reduction based on combined NHS and Independent workforce statistics Sep/Oct 2015 =11,266WTE)

⁸ Health and Social Care Committee (2019) First 1000 days of life. House of Commons. <https://publications.parliament.uk/pa/cm201719/cmselect/cmhealth/1496/1496.pdf>

7.5 Health visitors' skills: Health visitors are trained as “Specialist Community Public Health Nurses” with broad training standards set by the NMC. However, the level of training on child development and SEND is determined by the individual HEI, resulting in considerable variation in the knowledge and skills of practitioners. In addition, some local health visiting service specifications have reduced the “holistic review of child health, development and growth”⁹, to the completion of the Ages and Stages Questionnaire (ASQ-3) which relies on parental report, rather than a “hands on” holistic assessment. Unsurprisingly, there are accounts of developmental delay being missed due to the reported low sensitivity of the tool. To address this, the health visiting workforce would benefit from additional training/ CPD to ensure that they have the necessary skills and competencies to identify and support families where cerebral palsy is suspected – in recent years health visitors have reported variable access to CPD which is locally determined.

7.6 The Institute is here to help and should be involved especially in the delivery of local leaders including SEND specialist health visitors for the profession. We set national standards and can work with employers to ensure the proposal is implemented as necessary and health visitors are able to operate to a high standard. We can also offer our own Vision for health visiting¹⁰ as a blue-print for health visiting services in the future which received widespread endorsement by stakeholders across the health and social care system (see “Health Visiting in England: a vision for the future” 2019, for full list)¹¹. For example:

“Health visitors act as a frontline defence against multiple child health problems... [they] are an important cog in the wheel that allows the child health service to effectively function. However, thanks to sharp public health spending cuts, numbers are falling dramatically and this is having a detrimental impact on infants and children”.

Prof. Russell Viner, President of the Royal College of Paediatrics and Child Health (RCPCH)

“Health visitors are an essential part of the country’s support structure for young children and their parents – especially those who are struggling to cope. But they can only do this if they have the time and capacity to develop good, trusting relationships with families. I am very concerned that the huge pressure on health visitor services is making it harder for them to do this, meaning some vulnerable children are in danger of falling through the gaps.”

Anne Longfield, Children’s Commissioner for England

⁹ Public Health England (2018) Best start in life and beyond: Improving public health outcomes for children, young people and families. Guidance to support the commissioning of the Healthy Child Programme 0-19: Health visiting and school nursing services Commissioning guide 2.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/716028/best_start_in_life_and_beyond_commissioning_guidance_2.pdf

¹⁰ Institute of Health Visiting (2019) Health Visiting in England: a vision for the future. <https://ihv.org.uk/our-work/our-vision/>

¹¹ Institute of Health Visiting (2019) Health Visiting in England: a vision for the future. <https://ihv.org.uk/wp-content/uploads/2019/11/7.11.19-Health-Visiting-in-England-Vision-FINAL-VERSION.pdf>

8. Further information

A diagrammatic representation of the work of the health visitor across a breadth of policy priorities providing a universal “safety net” for vulnerable babies and young children.

