Down Syndrome Act 2022 guidance: call for evidence
Written evidence submitted by the Institute of Health Visiting

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1. About the Institute of Health Visiting

The Institute of Health Visiting (iHV) is an independent charity, professional body and Centre of Excellence – established to strengthen the quality and consistency of health visiting practice, so that health visitors can effectively respond to the health needs of all babies, children, families and communities enabling them to achieve their optimum level of health, thereby reducing health inequalities.

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.

Health visitors (HVs), as Specialist Community Public Health Nurses, provide an important and non-stigmatising safety net for infants, through their universal reach into all families and input across the whole health and care pathway for families with babies and young children with Down's syndrome.

2. Our key points

The evidence base of what families with babies and children with Down's syndrome value from health and related services has increased in recent years and should be acted upon in the design of services including health visiting. People with Down's syndrome have a genetic variation. Whilst they share some common features, it must be emphasised they are all individuals with their own abilities, needs, interests and aspirations. Down's syndrome is not a disease and people who have Down's syndrome are not ill.

We provide evidence in response to the questions for **professionals, about health services,** and in relation to the health visiting service in England:

2.1 Do you agree or disagree that the staff at your organisation understand how to support the specific needs of people with Down's syndrome?

We provide evidence that action is needed to increase the health visiting workforce's capability, and capacity, to better support families with children with Down's syndrome:

- **The iHV has led two national research projects, funded by Health Education England, on 'Delivering Different News'[1]** in the context of Down's syndrome – these commenced in 2017.
  The first 1001 days, covering from pregnancy to the time that a child is two years old, are critical for children's physical, emotional and cognitive development. Families are vulnerable when congenital anomalies are identified, as this presents a different parenting journey from their expectations. Ineffective delivery of this 'different news', and the news itself, can result in depression or anxiety in parents. This may impair parenting ability which potentially has a direct immediate and long-term impact on the infant's physical, cognitive, emotional and social development. Different news must be delivered sensitively and compassionately by professionals.

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[1] Mugweni, E (2021) Preventing mental ill-health across the life course when healthcare professionals deliver different (unexpected) news to families in the first 1001 days of life https://ihv.org.uk/news-and-views/voices/preventing-mental-ill-health-across-the-life-course-when-healthcare-professionals-deliver-different-unexpected-news-to-families-in-the-first-1001-days-of-life/

This does not always happen due to a lack of standardised training or policy in this area. Parents must receive Different News from healthcare professionals (HCPs) with skills to deliver the news sensitively and compassionately. Currently, not every family has access to such HCPs due to a lack of standardised training or policy to guide professionals on how to effectively deliver this news. Providing communication skills training can potentially minimise the negative psychological impact of the news, maximise the psychological wellbeing of the whole family and reduce staff burnout.

Working with parents with the lived experience of receiving different news and healthcare professionals, we developed a training intervention that equips professionals to: demonstrate empathy; compassion; utilise kind, simple and truthful language; answer questions; and signpost to further support using a mnemonic to structure and pace the conversation. Following the training, we found statistically significant improvements in confidence and skills to provide sensitive, responsive, balanced care to families. The training may equip professionals to minimise the psychological distress associated with receiving different news which can prevent mental ill-health across the life course. It is imperative to roll out the training nationally to ensure that families are adequately supported.

- **In 2019, the iHV completed a project using co-production methods, with Down's syndrome charities and parents with lived experience**, to develop a suite of 'Good Practice Points' resources for health visitors' work with families with a child with Down's syndrome. As part of our scoping, families reported a postcode lottery of support – the quality of the service that they receive, and the skills of the staff that deliver it, really does depend on where they live; some families reported excellent levels of support, however others reported that they received hardly any support and practitioners were ill-equipped to support the specific needs of a baby with Down's syndrome and their family.

  The key themes arising from this work which was co-produced with parents, using their own words, were:
    - The language we use matters. Language implies positive or negative attitudes simply by the words chosen. These attitudes then influence perceptions of whatever is being discussed. When people with Down's syndrome and their families hear the syndrome being referred to as a 'risk' or 'abnormal' it upsets them, when they hear their child referred to as "a Down's boy" it grates and sends the subtle message that people don't understand their world. It is so important that we show people through our words that we are all more than our diagnoses and do not portray people with Down's syndrome as less than, or undesirable.
    - Some health issues are more common for people with Down's syndrome, therefore there are more checks for babies and children with this condition than for a typically developing baby. These include heart, digestive, thyroid, hearing and vision checks. People with Down's syndrome will also benefit from the same universal health visiting service and advice on ways to stay healthy as any other person (for example, healthy eating, vitamins and keeping active).
    - Parents find the health and care system complex to navigate and are often unaware of the services and benefits that they can access. Continuity of health visitor is important; families value "being known" and receiving personalised care. This requires practitioners with the skills and knowledge to support families to access the local offer in their area for children with Special Educational Needs and Disabilities (SEND), including health and care services, and other local resources and groups that suit their individual needs and preferences.

Action is needed to address the postcode lottery of support: Whilst there is national commissioning guidance for health visiting[2], it is quite 'high-level' and lacks detail on local service specifications or standards for specific groups like children with Down's syndrome (but applies equally to all children with SEND). Decision making on the quantity and quality of health visiting support has been devolved to local authorities since 2015 resulting in a postcode lottery of support. Funding for health visiting is provided through the **Public Health Grant** from the Department of Health and Social Care.

The Public Health Grant must be spent on the public health service areas specified in the 'grant rules' (such as interventions to tackle teenage pregnancy, child obesity, sexually transmitted infections and substance misuse, as well as commissioning Health Visiting and School Nursing services, and as such, is ring-fenced funding).

In 2022 to 2023, the total public health grant to local authorities was £3.417 billion. **Even with more recent uplifts in cash terms, the public health grant in 2021/22 was 24%, or £1 billion, lower in real terms compared to 2015/16.** This has led to reductions in vital services such as health visiting, stop smoking support and sexual health clinics, putting people at risk of poorer health and storing up problems for the future.

Action is needed to rebuild the health visiting workforce in England: There is currently an estimated national shortfall of 5,000 health visitors in England, following year-on-year cuts to the public health grant and insufficient student health visitor training places. This impacts on the workforce's capacity to provide families with the support that they need during these critical early years of a child' life. The health visiting workforce issues are summarised in the iHV annual health visiting survey report, 2021[3]. The consequences of cuts to the health visiting service are shortsighted as they have costly 'knock-on' consequences that impact across the whole health and care system; these are summarised in a report, 'Why Health Visitors Matter'[4] produced by the First 1001Days Movement of more than 200 organisations calling for investment in health visiting.

2.2 Do you agree or disagree that all staff who provide services or support to people with Down's syndrome, are aware of their legal obligations and duties in providing healthcare services to meet the physical or mental health needs of people with Down's syndrome?

As above, this varies between local authority areas.

2.3 What would be the most helpful things to include in the guidance for organisations providing services to meet the physical health needs of people with Down's syndrome and their families and carers?

Our response to this question on physical health, applies equally for the development of guidance to address the mental health needs of babies and young children with Down's syndrome and their families and should be applied to both questions. Any guidance should take account of the following key themes that are supported by the best evidence of 'what works':

1. **Ensuring that every child has the 'best start in life' needs to be a priority.** We have more evidence than any other generation on the importance of the earliest years of life – this is summarised in the following quotes from the leading researcher in health inequalities, Sir Michael Marmot (2010):

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[2] Public Health England (2021) Healthy child programme 0 to 19: health visitor and school nurse commissioning https://www.gov.uk/government/publications/healthy-child-programme-0-to-19-health-visitor-and-school-nurse-commissioning

[3] Institute of Health Visiting (2021) The state of health visiting 2021: we need more health viistors https://ihv.org.uk/wp-content/uploads/2021/11/State-of-Health-Visiting-Survey-2021-FINAL-VERSION-25.11.21.pdf

[4] First 1001 Days Movement (2022) Why health visitors matter. https://parentinfantfoundation.org.uk/wp-content/uploads/2022/05/Why-Health-Visitors-Matter.pdf

"The foundations for virtually every aspect of human development – physical, intellectual and emotional – are laid in early childhood. What happens during these early years (starting in the womb) has lifelong effects on many aspects of health and well-being– from obesity, heart disease and mental health, to educational achievement and economic status."

Sir Michael provides an important reminder for all policy makers that, *"health inequalities are not inevitable and can be significantly reduced" Marmot, 2010.*[5]

When babies and young children thrive, all of society benefits, and this requires a whole system response.

2. **Families' health and care needs vary across the life course** and are multifaceted, this includes parents of babies and young children with Down's syndrome. Families benefit from a **"whole person – think family" approach within a complex system of support** that is well-coordinated and responsive to their changing needs[6]. Conversely, fragmented care that is poorly coordinated, not tailored to individual needs, or takes a reductionist approach by reducing care to a series of tasks or isolated interventions/ services, all contribute to worse outcomes and families fall in the gaps between services.

3. **Getting it right from the start:** We make recommendations based on the findings of a large research project on 'Delivering different news' which highlights the importance of language and parental support around the screening process, at the time of diagnosis and during the earliest years of life. As stated earlier, families are vulnerable when congenital anomalies are identified and the impacts of poor support at this crucial time can be significant and impair parenting ability which potentially has a direct immediate and long-term impact on the infant's physical, cognitive, emotional and social development[7].

4. **The importance of the universal health visiting service:** The universal health visiting service aims to support healthy pregnancy, improve early childhood development, ensure readiness for school, and reduce health inequalities in young children. In England the service is delivered through the Healthy Child Programme which is a universal prevention and early intervention programme, based in an evidence-based framework for the delivery of public health services to families with a child between conception and age 5. The health visiting service reaches all families – with an intensity of support based on proportionate universalism. Health visiting practice is focused on 'health creation', using strengths-based approaches and personalised support tailored to the needs of the individual in context.

   Through their **universal** reach, health visitors are able to build relationships with families. All families have a health visitor which reduces any stigma associated with reaching out for help – the service also recognizes that babies are citizens in their own right and will proactively search for health needs which may be hidden, providing a vital safety-net for vulnerable babies and young children. A recent report, 'Early Moments Matter', by UNICEF UK, recognizes that, *"Health visiting is the backbone of early years services across the UK… the 'safety net' around all families"[8].*

   All children in England should receive five mandated universal health visitor Healthy Child Programme reviews. In some parts of England, families receive more contacts, and in Scotland the

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[5] Marmot M, Allen J, Goldblatt P, Boyce T, McNeish D, Grady M et al. (2010) Fair Society, Healthy Lives: The Marmot Review. Strategic review of health inequalities in England post-2010. London: Marmot Review; 2010. https://www.parliament.uk/documents/fair-society-healthy-lives-full-report.pdf

[6] 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

[7] Mugweni, E (2021) Preventing mental ill-health across the life course when healthcare professionals deliver different (unexpected) news to families in the first 1001 days of life https://ihv.org.uk/news-and-views/voices/preventing-mental-ill-health-across-the-life-course-when-healthcare-professionals-deliver-different-unexpected-news-to-families-in-the-first-1001-days-of-life/

[8] UNICEF UK (2022) Early Moments Matter. https://www.unicef.org.uk/wp-content/uploads/2022/10/EarlyMomentsMatter_UNICEFUK_2022_PolicyReport.pdf

Universal Health Visiting Pathway includes 11 contacts. The universal reviews provide a holistic assessment of physical and mental health needs, child development, social needs and safeguarding. These contacts provide opportunities for health visitors to build trusted professional relationships with families to support the early identification of need. A trusted relationship with a health visitor is important as it improves the accuracy of assessments and disclosure of need.

There is global evidence that universal and intensive home visiting provided by health visitors improves child health and development outcomes (see England's evaluation of the Healthy Child Programme[9] which showed statistically significant improvements in many relevant outcomes over the lifetime of the National Health Visiting Programme; and Scotland's recent evaluation of the Universal Health Visiting Pathway[10] that increased the universal provision to all families, with: increased coverage which was largely equitable across all socio-economic groups; the additional reviews identified new concerns for children without previous concerns flagged; parents reported a positive and trusting relationship with their health visitor; and families were better able to ask for and accept the support on offer.

5. **Brokering engagement in treatment/ interventions**: There is good evidence that the families who need support the most are also the least likely to access it, due to a range of factors. Health visitors can provide that link, joining the dots between the families in need of additional support and the services that can support them. This is particularly important for families with babies or children with Down's syndrome (or other SEND) who report that it is challenging to navigate the complex health and care system, and many families miss out on the support that they need. Health visitors can connect parents to other sources of local support and work across agencies to coordinate care across the system.

6. **Early intervention:** As child health outcomes are inextricably linked to the quality of early care, and the context in which children live, there is good evidence that early intervention and support for parents during the transition to parenthood, and the early years, improves parental confidence and child outcomes. Disadvantage starts early in life, the effects are cumulative, can impact across the life course and transmit from one generation to the next, if not addressed. The cost of failing to intervene early is enormous. This is felt in human suffering and lost potential, as well as placing a burden on the Treasury to cover the increased costs of late intervention and the knock-on consequences for other parts of the health and care system that can last a lifetime.

7. **Personalised care:** Like all children, children with Down's syndrome are all different and will benefit from early intervention that is personalised to their identified needs. Child health outcomes are affected by a range of risk and resilience factors (including child factors, for example the presence of co-existing disease or other disabilities; and parental factors like mental health problems, domestic abuse, substance misuse and poverty that can all affect parenting capacity to a greater or lesser extent).

   Personalised support for babies/ young children with Down's syndrome (and all other SEND) **and their families** should be in place as soon as the early signs are detected – for Down' syndrome this is likely to be at the antenatal screening when a 'high chance' of Down's syndrome is detected. The period before diagnosis is often highly stressful for families and should not be overlooked. All parents are different and will respond to the diagnosis in an individual way. It is therefore extremely important that professionals take their lead from the parents. When parents are told that their baby has Down's

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[9] PHE (2016) Review of mandation for the universal health visiting service https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/592893/Review_of_mandation_universal_health_visiting_service.pdf

[10] Scottish Government (2021) Evaluation of the Universal Health Visiting Pathway in Scotland Phase 1 Report https://www.gov.scot/publications/evaluation-universal-health-visiting-pathway-scotland-phase-1-main-report-primary-research-health-visitors-parents-case-note-review/documents/

syndrome it can come as a shock, and there can be a process of grief and mourning for the baby that they were expecting to have. Equally, some parents may not experience this.

Specific guidance for babies and young children with Down's syndrome will be needed in the following areas:

- **Growth** – Babies with Down's syndrome can sometimes gain weight slower than other babies. There are specific growth charts for children with Down's syndrome as their growth follows a different trajectory and these should be used routinely.
- **Infant feeding** – Breastfeeding a baby with Down's syndrome is not only possible, it also provides important benefits to both mother and baby. However, there are some specific physical characteristics of babies with Down's syndrome that may have an impact on breastfeeding. Every baby is unique so not all of the challenges that are well documented will be relevant to every baby. It is important that staff have the skills to support breastfeeding a baby with Down's syndrome and if difficulties are experienced, additional support can make all the difference.
- **Child development** - There is no such thing as a typical child with Down's syndrome. Children with the syndrome are as different from each other as are all children. However, there are often delays in reaching developmental milestones, including communication and learning to walk, but strengths in reading and social interaction. Children with Down's syndrome also find learning from listening more difficult than learning through seeing. Advances in intervention have meant that very many children can enjoy a mainstream education in primary and secondary school.

  Children with Down's syndrome should receive all the universal health reviews. Public Health England's High Impact Area guidance for the 2-2.5 year review states that: "Where a child already has an identified disability or developmental delay, health visiting teams will need to agree with parents whether they wish to complete the ASQ-3TM (British English) questionnaire as part of their child's 2 year review. Much rests on health visitors' professional judgement and their skill in working sensitively and collaboratively with families to agree the best approach".

  The Down's syndrome inserts for the Personal Child Health Record (red book) contain charts which follow the usual developmental progress of children with Down's syndrome – these are used alongside health visitors' clinical skills and judgement to identify any additional needs. By understanding what is usual for a child with Down's syndrome, parents and practitioners are able to recognise any additional conditions at an early stage.
- **Managing minor illnesses and knowing when to seek urgent medical care**: Most children with Down's syndrome have some physiological and behavioural differences that can make it more difficult to assess the severity of illness. This infographic provides some useful advice that parents and practitioners need to be aware of: https://bit.ly/3KxFDpZ
- **Additional tailored support:** Babies and young children with Down's syndrome benefit from additional targeted support – in many areas this is provided by services like Portage. Although, action is needed to reverse cuts to services in some areas and ensure that there is equitable support available to all families, proportionate to need, across the UK.

Alongside our recommendations for guidance for services to meet individual's needs, we also offer the following recommendations to strengthen national policy to improve the support that families receive:

1. Current child health policy is fragmented. Policy join-up is needed across all child health policies including the SEND Review, 'Start for Life', the Healthy Child Programme, and 'Supporting Families'.

2. A national ‘statutory offer’ for babies, children and families with Down’s syndrome (and all other SEND) with clear pathways is needed across health and education whilst also maximising the opportunities of responsive integrated place-based approaches within Integrated Care Systems.
3. National standards should be co-produced with people with lived experience and practitioners to raise the bar from the current legislative standards.
4. SEND policy should be fully costed and sufficiently resourced by national government to ensure that it is implemented in full regardless of where families live.
5. Services need to have the autonomy to make quick decisions to reduce unnecessary delays. This should recognise the crucial role that the health visiting service plays in the early identification of need and brokering engagement in support, as well as the third sector in the provision of interventions (both pre and post diagnosis and EHCP).
6. Having sufficient workforce with the right skills, in the right place, at the right time will be central to success.
7. Frontline skills dilution presents a significant risk that requires urgent attention. Unless workforce shortages are addressed through demand-driven workforce modelling and planning, then no amount of strategy, partnership working or understanding of need is going to work. The loss of more than 1/3 of the health visiting workforce has had significant knock-on consequences for other services and requires urgent attention.

2.4 Do you think there are barriers in providing physical health services for people with Down’s syndrome?

yes

2.5 Do you think there are barriers in providing mental health services for people with Down’s syndrome?

yes

2.6 Do you think people with other genetic conditions benefit from the same health services used to support people with Down’s syndrome?

yes

2.7 Do you think there are differences in the physical health needs of people with Down’s syndrome and other genetic conditions?

yes

2.8 Do you think there are differences in mental health needs of people with Down’s syndrome and other genetic conditions?

yes