SEND review:
Right support, Right place, Right time
A response by the Institute of Health Visiting

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The Institute of Health Visiting's response to the government's SEND Green Paper consultation was led by Georgina Mayes, our Policy and Quality Lead, in collaboration with a range of stakeholders from across the sector and based on the best evidence of what works. We support the ambitions of the Green Paper's policy proposals to end the postcode lottery of SEND provision and our response aims to ensure that the needs of babies, young children with SEND and their families are recognised as early as possible and effectively addressed.

In our response to the consultation, we have sought to provide constructive feedback on the proposals and to suggest areas that we think the Department for Education and the Department of Health and Social Care should explore further. We have not responded to all the questions in this consultation; we have focused on the questions that are relevant to the health of babies, young children, and their families.

We recommend that the scope of the forthcoming policy is ambitious and extends beyond the Department for Education, with clear commitments and lines of accountability that extend across the multiple government departments that contribute to SEND outcomes. In particular, our response has focused on the vital contribution that health visitors bring to the success of the SEND programme. The need to improve the coordination of care for these families is well documented - health visitors are a skilled workforce who can support parents to navigate the complex systems of support.

What key factors should be considered, when developing national standards to ensure they deliver improved outcomes and experiences for children and young people with SEND and their families? This includes how this applies across education, health, and care in a 0-25 system.

- Give greater attention to the **first 1001** days which represent a crucial period of development and lay the foundation for lifelong health and success. Too little attention is currently given to this period, wasting an important opportunity to improve outcomes.
- Maximise opportunities to **prevent SEND** (e.g., by preventing the avoidable harms caused by alcohol and smoking in pregnancy).
- Improve the **identification** of babies and young children with SEND at the earliest opportunity. It is impossible to provide effective early treatment without this.
- **Support** for babies/ young children with SEND **and their families** should be in place as soon as the early signs are detected. The period before diagnosis is often highly stressful for families and should not be overlooked.
- **Improve access to early intervention** which can significantly improve outcomes. The consequences of delayed treatment are costly and can be life-limiting and life changing.
- The **health visiting** service has a key role to play in all of the above areas through its universal reach to all families. Action is needed to address the estimated workforce shortage of 5000 health visitors (HVs).
- **Policy join-up** is needed across all child health policies including the SEND Review, 'Start for Life', the Healthy Child Programme, and 'Supporting Families'.
- A **national 'statutory offer' for SEND** pathways is needed across health and education whilst also maximising the opportunities of responsive integrated place-based approaches within Integrated Care Systems.
- **National standards should be co-produced** with people with lived experience and practitioners to raise the bar from the current legislative standards.

How should we develop the proposal for new local SEND partnerships to oversee the effective development of local inclusion plans whilst avoiding placing unnecessary burdens or duplicating current partnerships?

- A **national statutory offer** is needed - including prevention, early identification, brokering engagement in support/ care navigation, treatment and interventions.
- **Agreed quality standards, outcome measures and quality assurance levers** are needed to reduce the postcode lottery of support and to support integrated service provision. National government remains accountable for delegated SEND functions and the success of national SEND policy.
- SEND pathways should be co-produced with families living with SEND and based on the best evidence of what works (including stakeholders and parents from underrepresented groups).
- The voice of the baby/ nonverbal child should be captured through proxy measures including learning from serious incidents and research.
- 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.
- 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 Education and Health Care Plan (EHCP)).
- Having sufficient workforce with the right skills, in the right place, at the right time will be central to success.
- 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.

4. What components of the EHCP should we consider reviewing or amending as we move to a standardised and digitised version?

- The national template for the digitised EHCP should be co-produced with parents with lived experience of SEND and frontline practitioners to ensure that it is fit for purpose.
- Digital inequalities should be addressed as they further exclude underrepresented groups.
- **Data quality** is essential – accurate decision making relies on the accurate **identification** and **recording** of need (the adage of ‘if you put rubbish in, you get rubbish out’). This requires frontline practitioners with the right skills to spot the early signs of SEND. Digital advances cannot replace the human interface with families at this critical time. We currently have unacceptably high rates of late diagnosis of babies and young children with neurodevelopmental conditions – care needs to be taken to ensure that digitisation does not make this worse.
- **Services need effective IT systems with interoperability** to support effective information sharing across all digital platforms and an integrated approach to social care assessments and EHCPs. This should include the new digital Personal Child Health Record and health visitors’ assessments.
- **Decision making** - There is currently no artificial intelligence with sufficient sensitivity or specificity to interpret data from multiple sources and replace human decision making.

- **Digitisation should enable improved access to early support** following the identification of need – mechanisms are needed to ensure that the assessment processes within services are not seen as 'gate keeping'.
- **EHCPs should include support for parents/carers themselves** and to help them navigate the complex SEND system for their child. The period from the first signs of possible SEND and through the process of diagnosis can be a time of enormous stress for families. Getting the right, personalised support can make a big difference during this period of transition and to long-term outcomes.
- **Actions are needed to reduce long waiting times for formal SEND assessments**. This requires demand-driven workforce modelling and planning to ensure sufficient workforce capacity across the whole pathway, now and in the future.
- **A 'whole child - whole system' approach to funding for SEND is needed**. Policies are fragmented across government departments, with disparate funding streams that hamper integration. Identifying who should pay for which service can be complex and is not helpful. Consideration should be given to an integrated health, education, and social care budget to prevent the support needs of babies and children being fragmented and potentially not being met, due to funding limitations in one agency.

6. To what extent do you agree or disagree with our overall approach to strengthen redress, including through national standards and mandatory mediation?

- We agree with the proposal to develop national standards and a statutory national offer/ model SEND pathways and strengthen redress. This should be based on the best evidence and avoid a 'race to the bottom/ lowest common denominator'.
- We also agree that mediation can be helpful, but it must be oriented to improving outcomes.
- Mandation has not proved to be effective in improving quality/ outcomes when used to address issues elsewhere. For example, the mandation of the health visitor universal assessments led to perverse system disincentives to 'tick the box but miss the point' to achieve compliance to an external body, but it did not achieve the desired outcome of improving the identification of need, improved access to support or reduced inequalities/ better health outcomes - in fact, it made things worse.
- Our consultation with stakeholders identified strong objections to mandation as it is:
    - not seen as a compassionate approach;
    - 'top down' - rather than focused on partnership and strengths;
    - often not independent.
- Mediation and advocacy should be an integral part of a collaborative and solution-focused process, rather than a last resort for unresolved problems.
- Workforce training in 'partnership working' is needed to support strengths-based practice that is built around trust and respect. Disagreements should be viewed as 'normal and expected' elements of effective partnership working and practitioners should be equipped to work positively with families throughout the process – this takes a high level of skill that should not be underestimated. Recent co-production with SEND families has highlighted that they often don't feel listened to or weren't offered timely support to meet the needs of their child. Families want to be listened to and heard, with practitioners working with them to develop a personalised package of support to achieve the best outcomes for them and their child (not a 'one size fits all' for any child).

- There is often a tension with finite budgets/ workforce which drives the prioritisation of services and packages of care that cannot be ignored. Prioritisation has a human cost. Compassion should be at the heart of all care – if a service cannot be provided, other options should be considered with the family, including support from the third sector and charities.
- Support needs to be centred on the needs of the child. Changing 'what can we do for your child (expert model)' to 'what does your child need? (support provided closest to the child – see Scotland's proximal model)' – this should take account of the context in which families live, the support that they can provide themselves, wider community support, augmented by professional support.

8. What steps should be taken to strengthen early years practice with regard to conducting the two-year-old progress check and integration with the Healthy Child Programme review?

- **The Healthy Child Programme (HCP) reviews need to be provided to all children**. Latest data from OHID (May 2022) highlights that more than 1 in 4 children are missing out on their two-year review – this needs to be taken seriously as it leaves vulnerable children invisible to services that can support them and has been flagged as a national cause for concern by the recent Care Review.
- **Clearer quality specifications** - The current service specification for the HCP review is too broad and non-specific - this has led to wide variations in service quality. The Ages and Stages questionnaire is only part of the assessment and should support clinical decision making by a practitioner with the right skills to assess the breadth of a child's needs (physical health, mental health, development and growth – as well as wider family factors/ social determinants of health and safeguarding) to identify vulnerable children and those at risk of poor outcomes.
- All children should be seen face to face – telephone and postal contacts should not be counted in data returns as this has masked workforce shortages and undermined service quality. Poor quality reviews also drive poor service uptake – parents 'vote with their feet'.
- Health visitors (HVs) are specialist public health nurses that are widely trusted and acceptable to families. They are trained to complete holistic assessments, spot nuances and deviations from the norm and identify problems early. HVs are highly skilled at having sensitive conversations and working with families who do not have the agency to seek support when needed.
- Early intervention relies on the early identification of babies and young children at risk of poor outcomes. Without an acceptable universal mechanism of identifying these children who are often invisible to services, all strategies will struggle to reach underrepresented groups.
- Consideration should also be given to following areas:
    - Integrating services through family hubs
    - Involving the right professionals, alongside HVs and EY practitioners - for example when a specific SEND is known (e.g., teachers of the deaf for children with hearing loss, physiotherapists for children with neurodevelopmental conditions like cerebral palsy).
    - Continuity of carer/ HV – particularly for children with SEND.
    - Interoperability and information sharing across agencies.
    - Clear roles and responsibilities for addressing identified need.
    - Replacing the Ages and Stages questionnaire (ASQ) with an agreed, validated assessment tool for early childhood health and development that is normed to the UK population and free from extortionate licence fees and poor performance/ quality issues that have dogged the ASQ.

  - A focus on quality improvement – Understanding and improving families' experiences, improving identification of need and child outcomes, and embedding learning from serious incidents including the findings from the Care Review and Inquiry into the death of Star Hobson.
  - Meeting the needs of children from underrepresented groups and those children who don't attend nursery or aren't brought to appointments.

17. What are the key metrics we should capture and use to measure local and national performance? Please explain why you have selected these.

- **A nationally agreed, simple shared outcome framework** is needed with the following components:
  - Expected outcomes for 2-year-olds.
  - Agreed national areas of focus to tackle the most pressing health and education inequalities (similar to the NHS Core20plus5 initiative). The ultimate measure of success will be the impact of collective efforts to reduce inequalities and improve outcomes for 2-year olds through focused efforts at all levels of the system - across national government department collaborations and through integrated working at the local level.
  - Having a 'whole system' shared vision/ ambition will help to move away from silo working, focus efforts on improving the areas of greatest need and will enable better collaborative working between agencies with a shared sense of purpose. For example: shared outcomes for school readiness across health, education and social care.

- **Process metrics** provide an important measure of reach, but used in isolation they lack information on service quality or outcome – useful process metrics include:
  - Service uptake – numbers of children receiving universal health reviews/ EY progress checks within specified age cut-offs.
  - Outcomes of assessment - whether a need was identified or not.
  - Recommended action - for example referral/ further assessment etc…

- **Child level data** – is needed to link data across the system through a unique identifier and to track progress, inputs and outcomes over time:
  - Child development scores – currently ASQ scores/ above or below cut-off for 5 domains of child development (see earlier recommendation for an England measure of child development to replace ASQ).
  - Timeliness – time taken for children to be seen for further assessments/ intervention.
  - Provision of an intervention (recorded by type).
  - Impact of intervention on child development trajectory (repeated child development measures over time).
  - Transition – the number of children with unknown/unsupported SEND identified on school entry will be an important quality indicator for the early years and health visiting.

- **Parent/ carer reported outcome measures:**
    - * Are families getting the support that they need? Did it make a difference? This could be achieved through a simple 'goal rating scale' used at the local level (see Centre for Parent and Child Support for examples).

- **Wider family factors and social determinants of health:** These are non-child specific data (for example the presence of parental mental health problems, domestic abuse, parental substance misuse etc…) that have significant impacts on child development and health/ education and employment outcomes over time. These data provide important information on the context in which a child lives that form an important part of clinical and safeguarding decision making. Compliance with GDPR is important and has been achieved in some areas through data linkage and tagging of 3rd party information on the child's records. 3rd party information can then be redacted if information is requested by the child when they reach the age of consent.
- Consideration should be given to developing national metrics of family wellbeing.
- Reducing the number of looked after children with SEND should be a key priority measure.

20. What will make the biggest difference to successful implementation of these proposals? What do you see as the barriers to and enablers of success?

We currently have piecemeal child health and education policies, with opportunities to improve alignment across the following policies:

- **Start for Life vision**
- **Supporting Families**
- **Child protection reforms and changes to family help**
- **Disparities White Paper**
- **Mental health 10-year plan**
- **Maternity reforms.**

In particular:

- **Continuity of carer** is a national recommendation set out in the Better Births National Maternity Review (2017) and reinforced recently as a key driver of maternity failings in the Ockenden Review. Evidence from a number of studies has identified that providing continuity of carer improves the identification of need, engagement in interventions and safety critical outcomes for parents, families and their babies.
- **Focus upstream on prevention and the earliest intervention** - including during the preconception and antenatal period to prevent harms and improve outcomes at the outset through the reduction of foetal alcohol spectrum disorders, preterm birth and adverse pregnancy outcomes which are the leading causes of SEND. Health visitors (HVs) have a vital role in mitigating lifestyle risk factors such as smoking, alcohol and substance misuse in pregnancy. HVs can also promote the early uptake of antenatal care; immunisations and can detect neonatal risk factors, including brain infections and prolonged neonatal jaundice. HVs can also provide accident prevention advice to reduce traumatic brain injury.

- **Focus on families (parents and carers)** – children with SEND outcomes are significantly impacted by the context in which they live and the health and wellbeing of their parents/ caregivers. It is therefore essential that any support for children with SEND also includes support for families. Health visitors play a vital role in the identification of need and supporting families through transition to SEND parenthood, including 'joining the dots' between the families that need support and wider agencies that are best placed to provide this support.
- **Planning for the future, including the genomics programme** – Maximising genomics is a key national policy, but it has not been included in the Green Paper. Advances in genomics will enable babies, children, and families in the community to benefit from a more accurate and faster diagnosis whilst supporting improved quality of care. This will include the earlier identification of babies with SEND (and will include asymptomatic babies) and requires careful management by a highly skilled workforce. The health visiting service is ideally placed to support families through their diagnostic odyssey, but plans need to be started now to rebuild the HV workforce to ensure that it has the capacity to contribute to the effective delivery of genomic healthcare.

21. What support do local systems and delivery partners need to successfully transition and deliver the new national system?

To enable the local systems and delivery partners to successfully transition and deliver the new national system – the following areas must be addressed:

- **Funding** – The policy will need to be fully costed. There are concerns that the budget is insufficient to successfully deliver the reforms – the £70 Million budget pales into insignificance when compared with the backdrop of cuts to services intended to support families. 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 – these cuts have had a negative impact on the experiences of babies and children with SEND and their families, as highlighted in the Green Paper, and need to be reversed. National government must ensure that local authorities have the resources and means to fully implement these reforms locally.
- **Workforce planning** – A national workforce plan is needed to ensure that there is sufficient workforce capacity and capability to deliver this strategy in full. There is currently a significant workforce shortfall that cannot be ignored – this requires a coordinated and well-resourced workforce plan based on demand-driven workforce modelling. Without this, these plans will fail. Since 2015, when responsibility for health visiting was transferred to local authorities, it is estimated that at least 30% of the health visiting workforce has been lost, with further losses forecast. The decline in the workforce has put pressure on services, which has consequences for babies with SEND and their families across the country.
- **Coordination of national and local infrastructure** - Whilst a focus at strategic level is essential, so is the coordination of the infrastructure at a local level to ensure that services are provided and coordinated to meet the needs of babies and children with SEND and improve outcomes/ reduce inequalities. This should include a focus on seamless support and a reduction in the duplication of services. Collaboration and integration across ICS/ ICPs is needed to ensure that sufficient resources are allocated to deliver these reforms in full and to maintain an overview of the quality of services.
- **Quality assurance mechanisms** are needed to end the postcode lottery of support.

22. Is there anything else you would like to say about the proposals in the green paper?

The scope of this policy must be ambitious and include multiple government departments beyond the Department for Education.

In particular, our response has focused on the vital contribution that health visitors bring to the success of the SEND programme. 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. 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. Early identification of developmental disorders and disabilities is important to support prompt diagnosis and tailored interventions and support, including supporting parents through the process of adjustment when they receive "different news".

This includes supporting transition to parenthood for families who receive a diagnosis following antenatal screening as well as those whose conditions are recognised in the early years.

Children born prematurely are at particular risk of developmental delay and often show atypical patterns of development. Disabled children may have severe and complex needs that require health and social care support from a range of providers. This requires a joint, integrated, inter-agency approach at the point of delivery of health, social care and education. Supporting children with complex health needs, disabilities, and SEND is an important part of the universal prevention and early intervention programme provided by health visitors.

The need to improve the coordination of care for these families is well documented - health visitors are a skilled workforce who can support parents to navigate the complex systems of support. It is widely recognised that parents of children with complex health needs are at increased risk of experiencing additional stress; parenting a disabled child goes beyond 'ordinary' parenting. It is not surprising, therefore, that parents of disabled children are more likely to require support than parents of non-disabled children. Services which are accessible and offer a partnership approach where parents are involved in decision making result in improved parent satisfaction, decreased parental stress, and an improvement in child outcomes. Services need to be flexible and promote individualised care which requires that joint working is coordinated between the family and all practitioners involved. Health visitors also play a crucial role in supporting access to wider support (like uptake of Early Years provision, relevant disability and income-related benefits, and reducing parental conflict) as well as effective transition to school and the school nursing service (see iHV Vision for Health Visiting for references).

Cuts to health visiting services have had a direct impact on the timely referrals to specialist services with many reporting problems with late identification of SEND and wider vulnerabilities. Cutting skilled professionals to identify the early signs of SEND and reach the 'so-called hard to reach' is a false economy as any short-term savings are quickly offset by increased delayed treatment costs and, for some, the consequences can be catastrophic.

Strengthening the health visiting service requires a clear plan focused on the following three areas:

- **Funding**: Local authorities need sufficient funding to deliver the full Healthy Child Programme. This requires cross-department support as the benefits of an effective health visiting service accrue across multiple departments.
- **Workforce**: A national plan is needed to address the estimated national shortage of 5,000 health visitors (Conti and Dow 2021).
- **Quality**: National government must do more to end the postcode lottery of support and ensure that local authorities have sufficient resource to enable them to provide health visiting services at a level that delivers everything that government and NICE guidance expects of them, and that babies and children with SEND need.

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