

Written evidence submitted by Institute of Health Visiting

About us: The Institute of Health Visiting (iHV) is an independent professional body, charity and centre of excellence for health visiting – established to strengthen the quality and consistency of health visiting for the benefit of all babies, children, families and communities.

Our evidence is focussed on providing an effective, collaborative approach to SEND provision which keeps the needs of babies, children and families at the centre - improving outcomes and reducing inequalities. We focus on the vital contribution that health visitors bring to solving the SEND crisis. Our response is focused on Part I – we also provide some additional evidence for Part II, III and IV.

When adequately resourced, health visitors provide an important part of the solution in ensuring that families get good, joined up support. The benefits of an effective health visiting service accrue to numerous government departments, contributing to a whole system response to improve SEND provision¹.

Through their **universal reach**, health visitors work with **all** families from pregnancy to school entry. As registered and regulated Specialist Community Public Health Nurses, they are widely trusted and their support is welcomed by families. With a **breadth of skills** that straddle child and adult health (physical and mental health), child development, social needs and safeguarding, they can ensure that families get the right support, including during long waits for assessments in specialist services. In the NHS, early senior clinical decision making has been recognised as a crucial first step in effective care planning, identifying those with the greatest need to manage risks, improve outcomes and reduce costs in the long run.

Through home visiting, health visitors see the “whole child” in the context in which they live; this provides valuable insight into their unique strengths and difficulties. During their universal and targeted contacts, health visitors strive to develop relationships and work in partnership with families, to create a personalised plan of care that meets the needs of the child.

Their ability to reach all families is particularly important for those on the margins of society that are often invisible to other services. Through their knowledge of local health systems and wider support, health visitors also play an important brokering role, connecting families to other services and resources to meet their needs. Health visitors have been described by Unicef-UK as the **“backbone of the early years... the safety-net around all families”**².

Part I: Improving support for babies and young children with SEND

1.1 Outcomes for children and young people with SEND and how these can be improved:

Our recommendations are based on key messages from research and evidence-based practice on the core components of effective health visiting services:

- **Prioritise the critical earliest years of life**

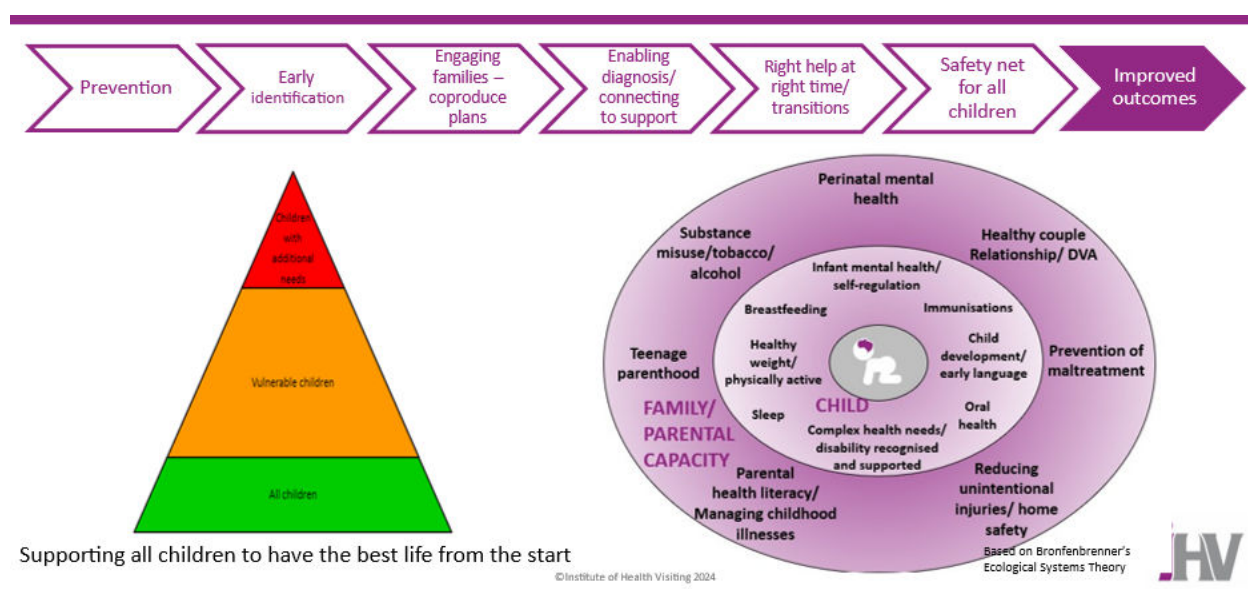
Solving the SEND crisis needs to start long before children start school. The earliest years of life, including the preconception period, pregnancy, infancy and early childhood represent a critical window to shape a child’s physical, emotional and cognitive development. There is strong evidence that exposure to certain environmental risks during this critical period can have significant consequences on an individual’s short - and long-term health and development. Where people are born, live and grow, whether they are rich or poor, and the support that they receive from their

families, communities and the services around them, can also all make a big difference to an individual's life chances. Prioritising spending on prevention and early intervention in the earliest years has been shown to yield the greatest return on investment in the medium to longer term.

Currently, too little attention is given to the earliest years, with a well-recognised policy “baby blind spot”³, wasting an important opportunity to improve outcomes. We make the case that babies and young children should have the same parity of SEND support as school aged children and young people. Babies and young children are at risk of falling in the gaps between “health” and “education” policy priorities in different government departments. In our view, better join-up is needed, with policy and services centred on the needs of babies, children and families, and cross-departmental working to achieve ambitious shared SEND outcomes. We welcome the announcement of the recently appointed experts to advise the Government on SEND reforms in schools⁴ and call for equivalency for the early years.

- **Maximise the role of health visitors across multiple points in an integrated pathway of SEND provision:**

Figure 1: The role of health visitors across an integrated SEND pathway of provision



Health visitors have a vital role to play at different points across the SEND pathway (see Figure 1), including:

- Primary prevention** – supporting families to reduce risk factors to prevent disease or injury. For example, through pregnancy and preconception care to improve pregnancy outcomes, reduce foetal alcohol spectrum disorder, preterm birth and genetic risk factors through genomics. And during childhood, they can prevent severe traumatic brain injury through their work to prevent accidents and abusive head trauma (“shaken baby syndrome”) that can lead to cerebral palsy.
- Secondary prevention/ early identification/ needs assessment** – reducing the impact of a condition and the likelihood of more severe issues developing over time. Through their universal and targeted work, health visitors are ideally placed to identify babies and children with atypical or disordered patterns of development, or with significant impairments likely to result in disability. Using their clinical skills, they can also identify “risk factors/ red flags” for serious conditions that can be mitigated, for example through the identification and effective management of neonatal jaundice to reduce avoidable harms that can cause cerebral palsy, hearing loss and learning disabilities in severe cases if untreated. Health visitors can quickly

refer families to paediatric services, preventing the “wait and see” delays that can have catastrophic consequences if warning signs are missed⁵.

- iii. ***Tertiary prevention*** – supporting families to manage long-term, often complex conditions to improve their quality of life. And connecting families to wider system support, specialist health services and targeted support to meet their individual needs from the VCSE sector.
- iv. ***Reaching all babies and children with SEND/ improving access/ safety-net:*** Health visiting is the only service that proactively and systematically reaches all babies and young children, bringing wider system benefits. The very best SEND interventions will only be effective if our services reach those who need them. Improving access to early support can significantly improve outcomes.

Health visitors are often parents’ first point of contact when they have concerns about their child’s development. Some families, especially the most vulnerable, may not be aware of the extent of their child’s health or development needs, or services to support them. There is a longstanding “inverse care law” whereby, perversely, people who most need care are least likely to reach out for support or receive it. The importance of a service that sees all babies and young children in-person cannot be underestimated. Babies and young children with SEND are often invisible to other services unless their caregivers reach out; unable to advocate for themselves, they are our most vulnerable citizens. Health visitors’ universal mandated contacts provide a vital safety-net for babies and young children - ensuring every child is seen is crucial.

- v. ***Engaging and supporting parents – the importance of continuity of carer:*** Parents play a vital role in supporting their baby/child’s development and engagement in SEND provision. Yet, we also know that many families are themselves struggling with a range of economic, social and personal health issues which can impact on child outcomes. And there are growing concerns about the number of invisible vulnerable children^{6 7}, and those who are not “ready for school”⁸. It is therefore vital that we do not consider the child in isolation. Alongside supporting the child, services must also consider the needs of parents/ primary caregivers and ensure that they are supported to thrive in their role.

Being a parent of a child with SEND brings many challenges. Families are vulnerable when signs of SEND are identified, as this presents a different parenting journey from their expectations. Ineffective delivery of this “different news”, the news itself, and uncertainties about how they will manage can result in depression or anxiety in parents⁹. This may impair parenting ability and can have a direct immediate and long-term impact on the infant’s physical, cognitive, emotional and social development. It is therefore vital that services also support families in their transition to parenthood on their “different journey” – health visitors play a key role in brokering parental engagement and providing support.

- vi. ***Enabling diagnosis – connecting to support:*** The impacts of long waits for assessment, diagnosis and treatment for babies and children can be devastating and this can be a particularly anxious time for parents. Addressing issues early can significantly improve a child’s developmental outcomes. Support for babies and young children with SEND and their families should be in place as soon as the early signs are detected – and this includes the period when they are waiting for specialist support and diagnosis.
- vii. ***Providing increased targeted support for high-risk groups:*** For example, babies born prematurely, and those impacted by consanguinity, and parental substance misuse are at

particular risk of SEND. Health visitors can provide additional targeted support for families with severe and complex needs, and initiate a joint, integrated, inter-agency response.

- **Improve integrated SEND pathways which maximise the contributions of all agencies supporting children with SEND (including health visitors):**

We have been involved in the development of the recent NHSE cerebral palsy (CP) integrated commissioning framework; we recommend that this is used as a blueprint for an integrated national SEND commissioning framework, with considerable transferable learning that will be relevant for other SEND conditions. Without a clearly defined integrated SEND pathway and commissioning framework (both nationally and locally), there is a danger that SEND is seen as “everyone’s business” - with duplication, service gaps, lack of coordination, unwarranted variation and inefficiencies. A clear commissioning framework facilitates financial and workforce modelling to ensure that sufficient resource is allocated to support its implementation. The strength of the CP Framework is that it is clear about “role differentiation” and the important contributions of all key agencies. Like pieces of a jigsaw, when agencies work together and deliver seamless joined-up support at all stages of the SEND pathway, babies, children and families benefit.

- **Strengthen the Healthy Child Programme – health visiting model for England:**

To improve health visiting SEND provision, we make the following recommendations:

- i. ***Increase health visitor workforce capacity (see 1.2)***
- ii. ***Ensure that all babies and young children receive the mandated universal Healthy Child Programme reviews:*** currently almost one in four children miss their two-year review¹⁰. This is flagged as a national concern by the Care Review.
- iii. ***Strengthen the health visiting commissioning guidance,*** with explicit governance to reduce disparities between local authorities and drive high-quality healthcare.
- iv. ***Increase the number of universal health visiting contacts to eight***¹¹ - to improve opportunities for prevention and early identification of SEND; including a contact at 3½ years to support school readiness and transition to school. The current health visiting model in England provides far fewer universal contacts than the evidence-driven health visiting models in other UK nations¹².
- v. ***Non-face-to-face contacts should not count as mandated universal health visitor reviews in service delivery metrics:*** It is impossible to complete a holistic health and development assessment of a baby/ child over the telephone or on a video-call – the practice increases risks and the chance that children with SEND will be unidentified. These universal reviews should assess physical and mental health, development, growth, family factors, and safeguarding, using UK-validated tools, alongside professional observation and clinical judgment. Counting non-face-to-face contacts produces misleading data, does not enable fair comparisons of health visiting performance metrics between local authorities in England, and provides false reassurance of the quality of health visiting service delivery in some areas; it also masks the underlying issues of insufficient funding, workforce shortages and poor-quality local service delivery models that are driving this practice.
- vi. ***Parents want continuity of carer:*** Relationship based care, rather than task-based care is more effective¹³, with good evidence that this leads to better identification of need, improved coordination of care, parental engagement and uptake of health promoting messages¹⁴ – this is particularly important for families with SEND, as well as under-served communities¹⁵.
- vii. ***Replace the [Ages and Stages Questionnaires](#) with a validated, UK-specific child development assessment tool and population measure,*** free of extortionate licence fees, that is normed to the UK population and has improved sensitivity and specificity – parents want assessments to be personalised and not a “tick box” exercise¹⁶.

- viii. **Strengths-based, child and family centred services.** Shift from “What can we do for your child?” to “What does your child need?” - support should build on parent/ family strengths.
- ix. **Family Hubs and health visitors should work together to coordinate care**, involving other professionals as needed (e.g., teachers of the deaf, physiotherapists) for tailored support.
- x. **Quality Improvement:** Focus on improving family experiences, identifying needs, learning from serious incidents; and with professional curiosity and actions to address barriers for children who miss appointments (shifting from “did not attend” to “were not brought”)¹⁷.

1.2 Workforce issues:

We support the government’s commitment to strengthen health visiting. Urgent action is needed to address the loss of more than 40% of health visitors since 2015^{18, 19}. This will ensure that every child can receive their mandated reviews, and provide enough health visitors to ensure they have manageable caseloads and can deliver targeted support for SEND. Strengthening health visiting is not complex – we need to get the basics right:

- i. **Train** enough health visitors to rebuild the workforce and replace those expected to leave.
- ii. **Retain** health visitors – plug the “leaky bucket”, attract people who have left back into health visiting, and improve opportunities for career progression, through leadership development and specialist posts.
- iii. **Reform** – put the needs of babies, children and families at the centre of health visiting care.
- iv. **Accurate workforce modelling, forecasting and planning** to mitigate against forecast workforce losses (40% of health visitors are intending to leave the profession in the next 5 years²⁰).
- v. **Strengthen health visiting SEND provision:** Health visiting practitioners recommended three top priorities that need addressing to enable them to provide high quality and effective care to all families of babies and children with SEND²¹:
 1. Ensure all areas have specialist health visitors for SEND to provide clinical leadership
 2. More health visitors
 3. Improved early identification and referral pathways which recognise the health visitor contribution.

Specialist Health visitors for SEND: are health visitors with additional post-qualifying training and experience in SEND. Specialist health visitors²² have key roles in providing local leadership and supporting high-quality service delivery, training and education, supervision, quality assurance, service improvement, and research. They:

- Act as champions and advocate for children with SEND within local systems.
- Promote a culture where families are seen as equal partners in care, ensuring their voices are heard in service planning and delivery.
- Lead quality assurance and evidence-based SEND practice. Use data to evaluate service effectiveness and identify areas for improvement.
- Lead service quality improvement and contribute to research and policymaking (developing local SEND pathways and enhancing family engagement strategies).
- Provide expert SEND training for generic health visitors and skill-mix team practitioners, alongside early years practitioners, and other professionals.
- Clinical supervision and mentorship – supporting learning and decision making in practice.
- Lead and facilitate collaborative working between health, education, and social care to create integrated care pathways.

1.3. Training in SEND

Supporting SEND requires a range of practitioners; and all staff must work within their level of skills and competencies to preserve safety and protect the public²³. Training is essential to ensure all staff

have the right knowledge, skills and competencies to provide safe, high-quality care, meet regulatory standards, and keep up to date. This is particularly important in healthcare – health visitors are registered practitioners with training and standards regulated by the Nursing and Midwifery Council to protect the public.

Having the right practitioner with the right skills at the right time is the bedrock of safe and effective care²⁴. This is particularly important when skills are needed for assessment, healthcare planning, risk management and child safeguarding which involve “pulling together the disparate parts of the jigsaw of a child’s life”²⁵. The workforce must be recognised as “the biggest safety critical asset that we have”²⁶. Investing in staff development may seem counterintuitive when funds are tight, but equipping staff with the right skills can lead to better outcomes and reduced costs in the longer term.

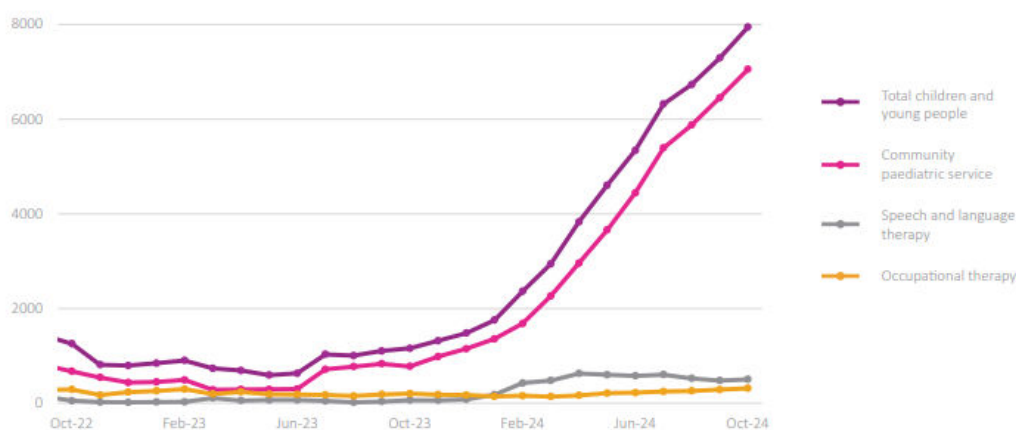
1.4. EHCPs: What can be done to support parents, carers and children before, during and after the EHC Plan process? How can the EHC Plan process be made non-adversarial?

In recent years, increasing numbers of parents have engaged in costly SEND disputes with local councils. In our view, taking a preventative approach, providing better “wrap around care” in the earliest years would ensure that families feel better supported; this will be an important part of the solution to improve support and reduce spiralling litigation costs (see our response to Part I, 1.1).

1.5. Current and future SEND need: How has SEND need changed over the last ten years and how will it continue to change over the next ten years? What does the DfE need to do to improve their current and future assessment of SEND need?

Use data to drive actions and address rising demand: Demand for SEND support is growing²⁷. NHS England data²⁸ show that the number of children waiting two years (104 weeks) or more for a community paediatric service more than tripled between February and October 2024, to 7,946 (see Figure 2). Most of these children will have SEND or suspected SEND and this presents a compelling case for investment in prevention, early intervention and effective support for families whilst waiting – as well as investment in the child health workforce to tackle backlogs in assessment, diagnosis and treatment. Childhood matters because it is short; and long waits for treatment and support are much more harmful for babies and children, compared to adults, since intervention is needed by a specific age or developmental stage to improve outcomes and reduce harm²⁹.

Figure 2: Number of children waiting at least two years for community and elective hospital services – October 2022 to 2024 (Source: NHS England, Health Service Journal)³⁰



iHV Annual Health Visiting Survey findings (published January 2025, England data cited)³¹:

- 84% of health visiting practitioners reported that demand for health visiting support had increased in the last 12-months (October 2023- September 2024).
- 74% of practitioners had experienced increased demand for support from families for child behaviour problems – with an increase in parental concerns around possible Autistic Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD).
- Almost half of our survey respondents (47%) reported an increase in requests for support for infants/ children with disabilities or complex conditions.
- Survey respondents also highlighted that many families were grappling with more than one issue, as family life has become increasingly complex.

Demand-driven workforce modelling is needed to ensure sufficient workforce capacity to respond to the scale of rising need.

Part II: Current and future SEND need and provision**2.1. How does SEND provision vary between local areas and what can be done to promote consistency of approach?**

There are big differences in the level of health visiting support between local authorities in England³². Families receive good levels of support in some areas, and barely any support in other areas. Too many babies and children with SEND are missing out on the vital support that they need to reach their full potential. Many families are missing out on mandated contacts or are receiving these contacts from practitioners who are not regulated health practitioners, due to depleted health visiting services³³. Families need equitable access to good quality health visiting support.

2.2. What can be done to improve the effectiveness of multi-agency and joined up working cross education, health and social care?

- ***Develop local SEND pathways*** (with national pathways and commissioning frameworks as guidance, see Part I, 1.1).
- ***Maximise the role of health visitors:*** When adequately resourced, health visitors can play a key role in supporting effective multi-agency working and smooth transition to school. Their role could be strengthened by including an additional mandated health visitor review at 3 ½ years; and metrics to track the outcomes of children with SEND identified in the earliest years, alongside numbers of children with SEND who were not known to services at school entry.

2.3. What is working effectively within the current SEND system and how can best practice be sustained or scaled up?

- ***Mechanisms are needed to support the dissemination of SEND best practice.*** There are some excellent examples where health visiting services are strengthening their SEND provision and supporting improved integration at a local level – see Hertfordshire case study³⁴
- ***Support for quality improvement initiatives,*** including:
 - Using digital tools to reduce administration, releasing time to care.
 - Quality assurance – using data and regular audits to monitor outcomes, adjust strategies, and identify areas for improvement.
 - More effective information sharing between organisations to improve coordination and quality of care. This is reliant on the interoperability of agencies' IT systems, alongside good

quality data and having the right staff to interpret data to support personalised care planning and clinical decision-making³⁵.

- Collaborative, locally-driven, shared projects are more effective than top-down approaches in driving change³⁶.
- Coproduction between system leaders, researchers, parents and practitioners to develop a national evidence-based SEND pathway. To support effective implementation, local buy-in, good inter-agency working and a strong evaluation arm will be needed to monitor progress and outcomes over the short and longer term.

Part III: Finance, funding and capacity of SEND provision.

3.1. What funding is currently provided and what is needed for early identification of SEND, including in Early Years settings? What actions or reforms are needed to achieve financial stability and sustainability, both in the short and longer term, across the SEND system?

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.

Considerations for a whole system funding approach:

- Urgent investment in SEND support across the whole system to meet the scale of need. Long-term investment will help services plan and build world class services, ending the uncertainty of short funding cycles.
- SEND policy and a national “statutory offer” should be fully costed and sufficiently resourced by national government to ensure that it is implemented in full regardless of where families live.
- Demand driven modelling is needed to support funding allocation. A needs-based funding model will ensure areas with higher requirements are not disadvantaged.
- The needs of babies, children and families must be at the centre of SEND provision, with system blockers removed to enable best practice and integrated healthcare. National standards should be co-produced with people with lived experience and practitioners working in SEND.
- Clear integrated national SEND pathways and commissioning frameworks that include health and education are needed, whilst also maximising the opportunities of place-based approaches within Integrated Care Systems. Services need to have the autonomy to make quick decisions to reduce unnecessary delays.
- All areas must provide health visiting services that reflect best SEND practice and meet the scale of need. “Local decision-making” should not be used to justify poor quality care; mechanisms are needed to hold failing areas to account.
- Reforms should focus on improving service quality and child outcomes, as well as efficiency – using robust evaluation methods to monitor the impact of change.

Part IV: Accountability and inspection of SEND provision.

4.1. How can Area SEND inspections of local authorities be made more effective?

Embed the [SEND Code of Practice: 0-25 years](#) statutory guidance:

This requires:

- ***Sufficient funding, and capacity in Early Years provision*** to ensure that all 2-year-olds receiving Disability Living Allowance can access appropriate free early education and settings have the resources to meet their needs.
- ***Improved coordination of care*** – health visitors are a skilled workforce who can support parents to navigate the complex systems of support.

- **More investment in initiatives such as care navigators** to ensure equity across the UK (implementing recommendations from ‘[These are our Children](#)’ and the SEND Code (5.17)).
- **Sharing best practice and innovations to improve SEND provision**; for example, the [Kent model of Care co-ordinators](#) and the [Hertfordshire County Council SEND academy](#).
- **Working together/ multi-agency working** - partners must agree how they will work together across education, health and social care from early childhood through to adulthood. Integrated Care Boards and NHS Trusts must inform the appropriate local authority if they identify a child with SEND, or probable SEND. Local authorities need to use the information provided to them to plan provision (SEND Code, 5.15).

Key actions for Government include:

- **Strengthen Ofsted and CQC oversight.** This includes ensuring inspectors are made accountable to governing bodies, and Ofsted inspections for Early Years Settings have more focus on the SEND support and provision they provide.
- **Develop clear national standards for SEND provision** –with robust system levers to end the current postcode lottery of provision.
- **SEND support in the early years should be statutory** and offered without discrimination. This includes the provision of support for parents and improved access to Early Years settings, with reasonable adjustments and support from specialist teachers where appropriate.

A very real challenge faced by many health services following the inspection process is addressing the findings from inspections, whilst still operating under tight budget constraints. National government sets the context in which local governments work. Where improvements are needed after a poor inspection outcome, a budget review with sufficient funding is needed to support the local authority to improve provision to achieve the required level of improvement.

January 2025

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