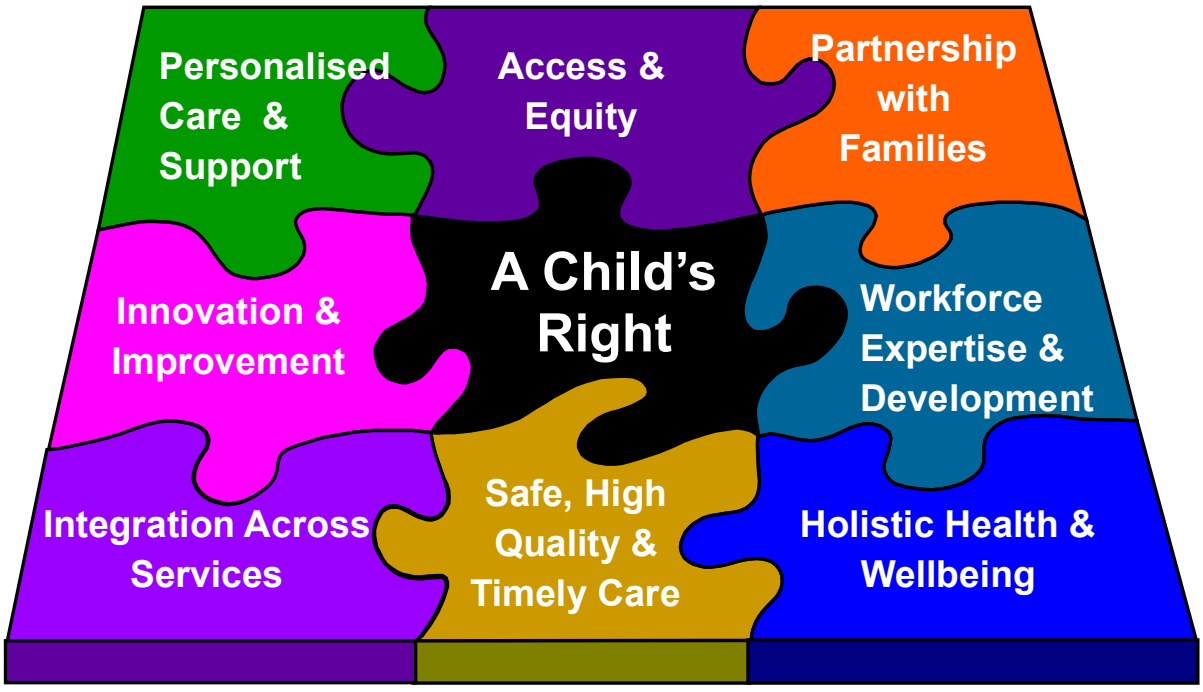
Association of British Paediatric Nurses

Briefing Paper on the key issues in the Independent Expert Panel Report on Palliative and End of Life Care in England



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Purpose

The purpose of this paper is to inform Association of British Paediatric Nurses (ABPN) members of the key issues from the Independent Expert Panel report on palliative and end of life care in England relating to children's[1] care

Background

The Health and Social Care Committee commissioned The Independent Expert Panel, to produce a report on England's palliative and end of life care services. The report was published on 28 November 2025.

What the report says about children and young people's palliative care

- The report highlights a serious issue with the commissioning and understanding of palliative and end-of-life care for babies, children and young people.
- While all 42 Integrated Care Systems had some focus on palliative and end-of-life care in their 2023 Joint Forward Plans, only 71% had "some focus" on children and young people's palliative and end-of-life care — meaning nearly one in three areas may lack formal planning for children's palliative care.
- Stakeholders — including charities and child-care experts — told the panel that there is a need for a dedicated paediatric palliative and end-of-life care lead within each Integrated Care Board. This means having clear clinical leadership and networks to ensure children's needs are understood and properly commissioned from the start.
- The panel heard that children's social palliative care is "not consistently commissioned or recognised across England," which suggests many families and children may not be receiving the support they should.

What this means for children and families

There is significant inconsistency across the country as to whether children's palliative care is formally planned and commissioned. Some areas may have

- weak or no formal provision for children and young people. This inconsistency in the quality and availability of care can result in a "postcode lottery."

[1] In this paper the term 'child' is used to refer to neonates, infants, children, young people and young adults up to the 25 years of age

- This variability in service availability undermines equity: some children with life-limiting conditions may lack access to essential care; families may face difficulty receiving the support they need, especially at home or outside working hours.
- The variation affects access to specialist consultants, community nursing, respite, bereavement support, short breaks and advanced care planning. Families in better-serviced areas likely have access to a broader "package" of care, not just sporadic support.

What needs to change?

- Creation of a clear children's palliative- and end-of-life-care lead within each Integrated Care Board, with connections to clinical leadership and networks — to ensure children's needs are properly understood, planned, and resourced from commissioning onwards.
- More consistent commissioning and recognition of children's social palliative care (not just medical/hospice care) across England — to avoid children and families being left unsupported.
- Efforts to address workforce shortages — particularly in specialist services for children/young people's palliative care and social care — because shortages limit the ability to provide appropriate high-quality care.
- The report notes particular concern that some areas provide better services for neonates/babies, while other Integrated Care Boards may not have clear arrangements — meaning newborns may face even more inequality, depending on where they live.
- There is little available data showing — for each region/Integrated Care Board — how many children actually receive palliative care (not just whether a service specification exists).
- For less well-covered areas, families may have to rely heavily on voluntary/charity-sector hospices, ad-hoc community nursing, or in worst cases, may receive no coordinated palliative care — contributing to inequality, stress, and potentially unnecessary hospital admissions or deaths in hospital.
- The broad funding variation signals that even within statutory services there's a systemic inequity — some Integrated Care Boards invest far more per child than others, leading to a "postcode lottery" not only in availability, but in quality and comprehensiveness of care.

Key Messages

- The independent expert panel emphasises that variation is unacceptable: whether a seriously ill child gets high-quality palliative care "should not depend on where they live."

- They draw particular attention to the wide variance in funding per child across Integrated Care Boards — from £397 down to £30.59 per child/young person aged 0–24.
- The independent expert panel flag the gap at specific crucial points: for example, neonates / very young babies may be especially disadvantaged in areas without robust commissioning; and transition from paediatric to adult services (around 18–19 years old) can also result in loss of support, because adult palliative care services are often not designed for young people with complex, childhood-onset conditions.
- The independent expert panel recommendations include more consistent, equitable commissioning; better national oversight (not just local Integrated Care Board discretion) to avoid postcode lottery; ring-fenced funding; and improved workforce supply to meet demand across all regions.

The ABPN calls for

- **Co-production in Service Development:** Integrated Care Board and service providers must ensure the voices of children, young people and families are heard and inform future development and optimisation of palliative and end-of-life care services.
- **National Standards, Oversight and Investment:** A nationally agreed framework with clear quality standards, expectations, and ring-fenced investment is essential. As Integrated Care Boards move into their role as strategic commissioners, the absence of national direction risks widening existing regional inequalities in children's palliative and end-of-life care. Children cannot be left dependent on inconsistent local priorities or variable funding models.
- **Integrated Care Board Accountability to Deliver Equitable Commissioning:** Integrated Care Boards must be required to prioritise and scale children's palliative care within their commissioning strategies. In areas where babies, children and young people's services are being integrated into all-age commissioning programmes, there is a significant risk that children's needs become diluted or deprioritised. Commissioning must be explicitly aligned with national paediatric palliative care quality standards, ensuring a consistent offer regardless of postcode.
- **Robust Data, Transparency and System Learning:** Currently, national visibility of children's palliative care is insufficient. Integrated Care Boards should be mandated to collect and report consistent data on access, equity, outcomes, unmet need, and the experience of families. Without comparable, transparent data across all systems, commissioners cannot identify gaps or demonstrate improvement over time.
- **Long-Term Sustainable Funding, Workforce Development and Training:** Short-term funding rounds and reliance on charity income undermine stability. The

workforce challenges, particularly for children's nurses, specialist consultants, and allied health professionals, require sustained national investment in training, development, and retention. A long-term funding settlement is essential to build and maintain the specialist skills required for high-quality children's palliative care.

- **Recognising the Wider Family and Societal Impact:** High-quality children's palliative and end-of-life care is not solely a clinical intervention, it profoundly shapes the wellbeing, resilience, and future contribution of the entire family network. The way we support families at the most difficult time has lasting effects on parental mental health, siblings' life chances, and the family's ability to participate fully in society. This makes children's palliative care not only a moral imperative but a strategic investment for communities and the wider health and care system.
- **Service development must include the nursing voice:** We call upon nurses working with children, young people and families to take advantage of opportunities to contribute and lead the development of the services needed to ensure equitable, accessible palliative and end-of-life care for this often-overlooked patient group.

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