

Families Kept Apart:

Parent accommodation on the neonatal unit in England



April 2024

Bliss is the UK charity that champions the right of every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.

Summary

- The lack of overnight accommodation for parents with a baby receiving neonatal care is a major obstacle to parents being primary caregivers, leading to increased stress and financial burden for families.
- Parental partnership in care is extremely important for bonding and positive outcomes for babies, but inadequate accommodation hinders the delivery of this care model.
- While there have been clear national commitments to make improvements in this area, these have not yet been delivered.
- Our research has found that for every 10 babies that need to stay overnight in neonatal care, there is only one room available for a parent to stay with them.
- Barriers to improving accommodation include lack of capital investment and physical space.
- We set out three recommendations:
 1. Update NHS guidelines to support the role of overnight accommodation for parents in family integrated care
 2. Develop a small grants programme to buy new furniture such as fold-out beds and privacy screens
 3. Provide capital investment to enable units to renovate or construct additional space for parent bedrooms and associated facilities.

Introduction

Parents of babies in neonatal care are not routinely provided with somewhere to stay with their baby overnight. This means that parents are usually separated from their baby repeatedly throughout their time in hospital. Bliss surveyed Neonatal Care Coordinators across England to understand what provision looks like and get their views on the barriers to improving the provision of parent accommodation.

Background

Family integrated care

Neonatal services in the UK strive to deliver family integrated care, a model of care which promotes a culture of partnership between families and staff. Evidence shows that parental involvement in care is critical for bonding and forming secure attachments. Parents who are supported to be with their baby for prolonged periods report increased parental confidence, and reduced stress and anxiety scores¹. Providing direct, hands-on care allows parents to feel like parents - which may be key for their perceptions of attachment to their baby - and physical and emotional closeness is crucial for forming strong parent-infant bonds². Research also underscores the positive outcomes of family integrated care for babies, including improved infant reflexes at term and better gross motor development at four to five years^{3,4}.

As part of this model of care, providing parents with the opportunity to stay on the unit overnight is of vital importance for parents and their babies; many parents tell us that being able to comfort or feed their baby during the night is a crucial part of them being meaningfully involved in their care. Services will never achieve 24/7 parental partnership if parents do not have even the most basic facilities to stay with their baby in hospital.

Previous Bliss research

In 2022, Bliss conducted research to understand the barriers that parents face to being involved in their baby's neonatal care. We found that 75 per cent of parents did not have access to overnight accommodation when their baby was critically ill and 87 per cent said this stopped them from being involved in their baby's care at least sometimes⁵. It was clear from these findings that neonatal services were struggling to provide the basic facilities that parents need to be partners in their baby's care.

Other Bliss research has also highlighted the huge additional cost of having a baby in neonatal care, a further obstacle to achieving family integrated care. The biggest additional cost to families was daily travel to and from neonatal units, with survey respondents spending £109 per week on average⁶. 84 per cent of parents using public transport said that access to transport stopped them from being involved as they wanted to be in their baby's care. This financial burden can have a long-term impact on family finances as one in four families told us that they had to borrow money or increase their debt because of their baby's neonatal stay. Parents being able to stay on the unit overnight when they want and are able can also mitigate some of these costs.

¹ Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial (O'Brien et al, 2018)

² Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU (Treherne et al, 2017)

³ Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial (O'Brien et al, 2018)

⁴ Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU (Treherne et al, 2017)

⁵ Method: self-selecting survey disseminated through Bliss social media and email newsletters, and via partner organisations in February and March 2022. 1928 respondents. Two focus groups conducted in March 2022 with a) dads (n=9) and b) parents who were on a low income/struggled significantly with finances during their baby's neonatal stay (n=5)

⁶ Bliss Briefing: Impact of cost-of-living crisis in neonatal care (Bliss, 2022)

Policy context

The Department of Health (2009) Toolkit for High-Quality Neonatal Services⁷ recommends that overnight accommodation should be provided for families whose baby is receiving intensive care, with one parent room per intensive care cot located within 10-15 minutes' walking distance of the unit. The Health Building Note for Neonatal Units (2013)⁸ reflects this accommodation requirement of one parent room per intensive care cot, and also includes a series of requirements for facilities to "be supportive of the needs of the family" including a parents' sitting room, family education area, and a play space for siblings.

Most recently, the updated NHS England Neonatal critical care service specification (2024) has set out that "facilities and resources must be available to enable parents/carers to be resident with their baby for as long as they want and are able to be" (pg. 15) to support a family integrated care approach⁹.

Acknowledging the need to develop family facilities on neonatal units, the 2019 NHS Long Term Plan committed to "invest in improved parental accommodation"¹⁰ (pg.49). This commitment was renewed in the Three Year Delivery Plan for Maternity and Neonatal Services (2023) to ensure that "parents are partners in their baby's care in the neonatal unit through individualised care plans utilising a family integrated care approach, together with appropriate parental accommodation"¹¹ (pg. 10).

However, despite the provision of this extensive guidance over a number of years, it is clear that even a basic level of facilities for families is still not being met – most recently, the Getting It Right First Time (GIRFT) National Speciality report into Neonatology found that only 30 per cent of Neonatal Intensive Care Units (NICUs) met the standard for overnight accommodation¹².

Methodology

To understand what facilities neonatal units currently provide for parents and what barriers they may be facing to improving these, we conducted a survey between November 2023 and January 2024. The survey was disseminated to Neonatal Care Coordinators in England by Operational Delivery Network (ODN) leads. As part of the development of the survey, we received feedback on the format and questions from three ODNs.

Nine out of ten ODNs participated in the survey, providing data from 87 per cent of units in England.

⁷ Toolkit for high-quality neonatal services (Department of Health, 2009)

⁸ Department of Health (2013) Health Building Note 09-03: Neonatal units

⁹ Service specification: neonatal critical care (NHSE, 2024)

¹⁰ The NHS Long Term Plan (NHS, 2019)

¹¹ Three year delivery plan for maternity and neonatal services (NHSE, 2023)

¹² Neonatology: Getting It Right First Time report (NHSE, 2022)

Results

What does accommodation provision look like in England?

To fully support parents to be partners in their baby's care, accommodation must meet the different needs of families and what works best for their circumstances. Whether that's a room in which parents can sleep on the unit with their baby, temporary beds cot-side in an open ward, or a parent flat outside the unit.

In our survey, we asked about a range of different overnight accommodation options and found:

- 350 rooms identified where both parents can stay on the unit. Out of 2778 reported cots across 140 units, this is only 13% of babies who can have both parents stay in a room overnight on the unit. Across the units, there were also a further 21 rooms available for one parent to stay.
- 34% of units reported that they had access to rooms for parents nearby, but outside the neonatal unit.
- 56% of units had temporary beds such as reclining armchairs or fold-out beds next to at least one cot.
- Only 17% of units allowed siblings to stay overnight.

"Being in the flat [in the NICU] meant I could spend as much time as I possibly could with Alice... finding every small way possible to bond and be her mum." Katherine, mum to Alice born at 39+3 weeks.

These results mean that **87 per cent of babies cannot have their parents stay in a room overnight on the unit, that is nearly nine in ten.**

Disaggregating the number of parent bedrooms by designation shows that **9 per cent of babies on a Neonatal Intensive Care Unit can have both parents stay** in a room overnight, compared to 15 per cent and 16 per cent in Local Neonatal Units and Special Care Units respectively. It was welcome to note that the number of parent bedrooms where both can stay overnight (350) did not differ significantly from those where only one parent can stay (371).

"It was torture and the most heartbreaking time leaving our baby each night... we were offered one night of accommodation in the hospital... this was only a single bed, my husband slept on the chair." – Mum to a baby born at 33 weeks.

The short-term options are also limited as **44 per cent of units do not have temporary beds** such as reclining armchairs and fold-out beds next to at least one cot.

Aside from accommodation on the neonatal unit, 34 per cent of hospitals have rooms available for parents nearby. These rooms may be on another ward or provided by a charity.

17 per cent of units allow siblings to stay overnight, and healthcare professionals told us this is usually only permitted in exceptional circumstances. Having space for siblings to stay over the weekend, for example, is important for family bonding and eases the logistical challenges of childcare that parents tell us are barriers to accessing neonatal care.

What are the barriers to improving accommodation?

We asked respondents to tell us about the barriers their units face to providing parents somewhere to stay overnight from a list of options. Those completing the survey were asked to select the 'biggest barriers'. As illustrated in Figure one, 100% of respondents said that the biggest barriers to providing parents somewhere to stay overnight were:

- Lack of capital investment to build overnight accommodation for parents.
- Lack of physical space on the unit and on the Trust estate to build overnight accommodation for parents.
- Lack of physical space on the unit for temporary beds.

See Figure one on the next page for the full list of barriers.

We also asked respondents to list three priorities for spending to improve accommodation. The most common priorities, identified using thematic analysis, were:

- Access to capital funding for increasing unit footprint.
- Access to grants to upgrade existing facilities i.e. laundry, kitchen and dining, counselling areas, bathrooms, sitting rooms and sibling play areas.
- Financial support for all families for things like meals, travel, and parking.

"There are so many little things that would benefit parents...things like access to parent toilets on the ward so we don't have to wait to be buzzed in and out." – Jessica, mum to a baby boy born at 31+5 weeks.

The final question asked for any further comments on the issue of accommodation. Topics raised that are not already reflected above include:

"I had to leave my baby daily to go home even though there were empty rooms because I lived close. It was only when I complained about my son's care I was allowed to stay." – Tasha, mum to Teddy born at 26+5 weeks.

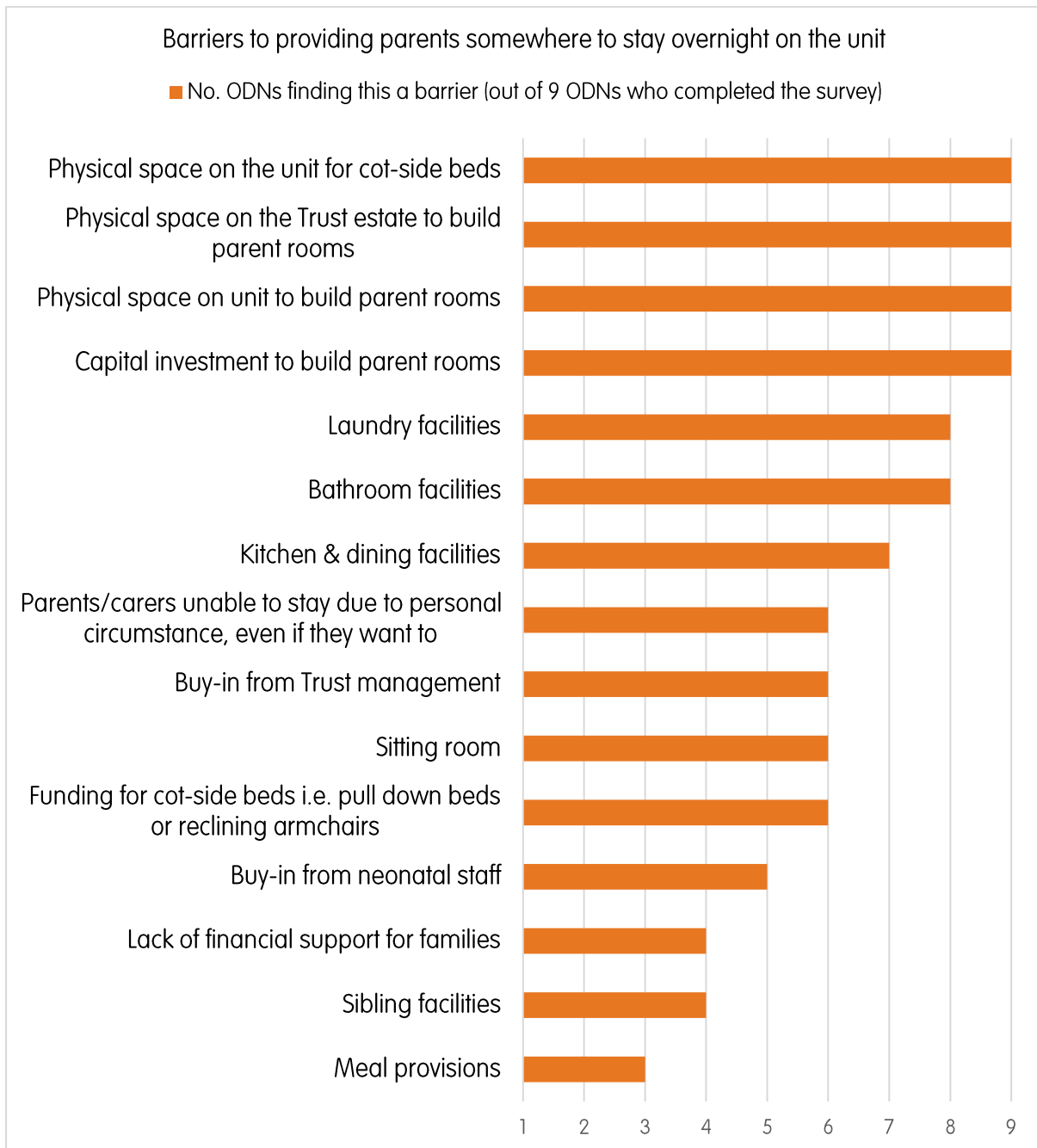
- Current standards for the provision of accommodation are not fit for purpose and don't encourage investment in facilities to support family integrated care.
- Policies about who can stay cot-side include risk assessments and eligibility criteria. This may exclude vulnerable families with safeguarding issues, reducing equality and access to care.
- Infection Prevention and Control guidance isn't consistent between Trusts so purchasing furniture for overnight accommodation for parents is difficult.

What is the urgency for improving accommodation?

We asked respondents to tell us if there are plans to reconfigure, renovate, or rebuild in their network and found that around **one-third of units already have plans for future works.**

Respondents shared whether they think their units will be able to fully support an increase in parental presence following the introduction of new neonatal care leave and pay entitlements in April 2025. While we very much welcome, and have campaigned for, this new entitlement, 67 per cent of survey respondents do not believe they have this capacity with their current facilities.

Figure one



Recommendations

1. Update guidance and establish accountability.

NHS England should update the guidance in the Health Building Note that units should have one parent bedroom per intensive care cot and ensure that Trusts are held to account to provide accommodation in line with the guidance.

The calculation of one parent bedroom per intensive care cot in the Health Building Note fails to acknowledge the benefits of family integrated care to all babies in neonatal care. Updating the NHS guidance would emphasise the importance of all parents being partners in their babies' care, regardless of level of care.

Establishing accountability for the provision of accommodation will ensure that where there are renovations and building works undertaken, these facilitate the model of family integrated care that services are expected to provide, as laid out in the service specification.

2. Invest in small changes with a big impact.

NHS England should develop a small grants programme so that Trusts can apply for funding immediately to buy new furniture or equipment to improve the neonatal environment and provide parents with the facilities to support them being partners in their baby's care, including the purchase of pull-out beds, comfy chairs, or privacy screens.

Many neonatal units could benefit substantially from small injections of funding to provide basic facilities that would have a high impact on the families they serve. Many units are not able to provide necessities such as cot-side comfy and/or reclining chairs, kitchen facilities, privacy screens, or fold-out beds even though parents are encouraged to spend all day, every day, at their baby's cot-side. Additionally, this can be an insurmountable barrier to mothers spending time with their baby post-birth injury or after a caesarean. Funding a scheme that units could draw on for these low-cost but high-impact facilities would be transformative for parents.

3. Capital funding.

The Treasury must identify the capital investment required to bring all parent accommodation up to a minimum standard on neonatal units in the next Spending Review.

Capital funding would give the units which have very limited space to accommodate parents, an opportunity to apply for capital funding to renovate existing spaces or construct additional space to be used as overnight accommodation rooms and/or facilities such as kitchens.

Over the longer term, the government should provide the capital funding needed for neonatal units that require larger sums of money to construct or completely renovate part of a building. This will allow neonatal units in this position to provide high-quality accommodation and facilities for parents when they need it.

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