Baby steps to better care Bliss Baby Report 2008



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Foreword

Last year around 82,000 babies in the UK needed specialist hospital care when they were first born. This is around one baby every six minutes.

For families, having their newborn baby admitted to neonatal care comes as a terrible shock and it is one of the most difficult experiences they will ever face. The care that babies receive is often life-saving and for many it will lay the foundations of their health for the rest of their lives.

This makes it all the more shocking that after four years of reporting on the problems in our neonatal services, we again find a service that is overstretched and understaffed. It is plain that neonatal units are still having to work at capacity and staffing levels that no other critical care service would permit.

During 2007 and 2008, the services for vulnerable babies in the UK have received more attention from the Government, the NHS and the media than ever before. In England an NHS Neonatal Taskforce has been created. In Scotland the Maternity Services Action Group has developed a series of recommendations to improve care. The Welsh Assembly has reopened an essential review on neonatal care. In Northern Ireland progress is gradually being made in developing essential transport services.

This progress is very welcome. However, these first small steps towards improving care must be supported and seen as part of a long term strategy to avert a potential crisis in neonatal care.

We are not alone in calling for action. Recently the National Audit Office, Public Accounts Committee, Healthcare Commission and the leading professional bodies have all highlighted the urgent need for investment in this critical area of care.

Healthcare authorities around the UK as well as the devolved Governments responsible for health have been failing babies, families and professionals for too long. They now have an unparalleled opportunity to make services for premature and sick babies a priority and to deliver much-needed change. We must start investing in all tomorrow's children today.

Andy Cole Chief Executive

Jala W



Executive summary and key findings

Bliss sent a survey to all the hospitals with a neonatal unit in the UK in early 2008, asking them about their activity in 2006 and 2007. We also asked nearly 500 parents a series of questions and to tell us about their experience of having a baby born sick or premature.

The resulting report looks firstly at neonatal care through the eyes of parents. When we asked parents to give their overall impression of neonatal care, eight per cent of them, unprompted, mentioned they experienced a lack of staff. These shortages can lead to transfers of babies between hospitals. Almost a third of parents with twins or triplets said their babies were cared for separately in different hospitals. This indicates that staff shortages are becoming a noticeable feature of families' time on a neonatal unit.

These shortages affect both doctors and nurses. One level 3 unit (Intensive Care) and 25 level 2 units (High Dependency) reported that they had no dedicated neonatal consultant. The number of neonatal nurses has increased by three per cent between 2006 and 2007. At the same time, the number of babies being admitted to care and the amount of care they require has increased by one per cent.

New evidence has been published supporting the view that the one nurse to one baby ratio should still be regarded as a minimum standard in Intensive Care. Fourteen out of 50 level 3 (Intensive Care) units said they had enough nursing staff to meet the needs of the babies they admitted, according to minimum nursing standards. This proves that the minimum standards are achievable. In order for this to be replicated across the UK by 2015, the current rate of nurse recruitment needs to be doubled.

Almost a third of all units in the UK worked at 100 per cent capacity or more, and over half said that they had to close to new admissions at some point in 2007.

When a unit does not have a staffed cot available for a baby, they may have to transfer them somewhere else. On average, three babies every day are transferred due to a lack of capacity in Britain's neonatal care units.

This is the fourth year that Bliss has reported on neonatal care services that are overstretched and understaffed. The difference this year is that it is not only Bliss who is calling for action on these problems. Official bodies both inside and outside the NHS are developing action plans and setting objectives. The Governments, the National Assemblies and the NHS need to be committed in the long term to building these services up – not just to the minimum standards, but to the best possible standards.

Recommendations

We make comments and recommendations specific to each UK country in the briefings which accompany this report. These can be found in the pocket at the front of this report and online at www.bliss.org.uk/babyreport2008. These recommendations should be applied across the whole of the UK.

- Neonatal care must be commissioned in complete compliance with BAPM 2001 standards. Babies
 are entitled to the same level of nursing care as adults and children in intensive care. Anything less
 than one to one nursing for babies in intensive care is unacceptable.
- Neonatal care must be seen as an integrated part of maternity services. Increasing the number of
 midwives, neonatal nurses and community neonatal nurses must be part of a long-term strategic
 plan to improve care for mothers and babies.

Introduction

Bliss is the only UK charity that helps care for premature and sick babies. We are dedicated to ensuring that more babies not only survive, but also go on to have the best possible quality of life. Bliss provides emotional and practical support for parents and families through what can be a traumatic time in their lives.

Families tell Bliss about their experience of having a baby born sick or premature and some of these experiences are included in the parents' section of this report.

We also work closely with the doctors and nurses who provide this vital care to develop solutions to the various problems that exist and to improve care for babies and their families.

In 2007, approximately 82,000 babies needed to be admitted to hospital for neonatal care. This represents around 11 per cent of all babies born in the UK and means that, on average, a baby is admitted to neonatal care every six minutes. This number is growing and each year the demand for specialist care for sick and premature babies increases.

What is a premature baby?

The average length of pregnancy is between 37 and 42 weeks. Any baby who arrives earlier than 37 weeks is known as premature. The majority of premature babies are born just a few days or weeks early. The earlier a baby is born, the more specialised the care they will need.

What is neonatal care?

Neonatal care is the specialist branch of medicine that looks after babies immediately after birth. Many babies admitted to neonatal care will have been born prematurely or born with low birthweight and will need some extra help until they are strong enough to go home. Others will have specific medical problems that require urgent specialist care or surgery.

How does neonatal care work?

Neonatal care is provided in specialist units that are graded into the three following levels set by the British Association of Perinatal Medicine (BAPM):

- A Special Care Baby Unit (SCBU) is known as a level 1 unit. Special Care is the least intensive, and also
 the most common. Babies in a Special Care unit may need to have their breathing and heart rate
 monitored. They may need to be fed through a tube, be supplied with extra oxygen or treated with
 ultraviolet light for jaundice. Special Care is also where babies who are recovering from more specialist
 treatment come to convalesce.
- A High Dependency Unit (HDU) is known as a level 2 unit. High Dependency is for babies who weigh less than 1,000g (2lbs, 3oz), are receiving help with their breathing via continuous positive airway pressure (CPAP) or intravenous feeding but who do not fulfil any of the requirements for Intensive Care (see below). A level 2 unit provides High Dependency as well as Special Care. This level unit can also provide Intensive Care, but only for short periods.
- A Neonatal Intensive Care Unit (NICU) is known as a level 3 or tertiary unit. These units are highly specialised and provide care to the most seriously ill babies. Babies in Intensive Care will often be on a ventilator and need constant care to keep them alive. A level 3 unit can provide all three levels of care and some will also have specialist surgery facilities.

This report takes an overview of neonatal care in the United Kingdom based on a survey of almost 500 parents and a survey of the country's hospitals.



Parents' stories

In June 2008, Bliss posted a survey on our website inviting parents to tell us about their experiences of having a sick or premature baby, and their opinions on neonatal care. We received 484 responses from a range of parents with different backgrounds and experiences. The 331 parents included in this chapter's analysis had babies born in 2006, 2007 or 2008. Eighty six per cent had a single baby and 14 per cent had twins or triplets. The average length of time that babies spent on the neonatal unit was nine weeks.

The most common message from parents was heartfelt and profound gratitude towards the nurses and doctors who provided often life-saving care for their babies. The words most used (unprompted) by parents when asked to describe the neonatal care they received were "brilliant" or "fantastic". The response of one mum is typical:

"Couldn't have asked for better care, love and support for both our son and we the parents. All the nurses and staff at the unit almost became like a second family to us and have a very large part to play in our son's life, as he wouldn't be here if it wasn't for such a great team of neonatal staff."

While the main message is immensely appreciative, the background to this is the emotional turmoil and upheaval that many parents experience when their baby is born premature or sick and enters a neonatal unit.

Experience of the unit

While most parents can expect to meet their baby immediately after birth, parents of premature and sick babies often have to wait hours and sometimes days to even see their baby for the first time. One in eight mums had to wait for two days or more to see their baby. This delay may often be due to a combination of the gravity of the baby's condition and the health of the mother, who may be too unwell to be moved.

In such stressful and upsetting circumstances, it is vital that parents are kept well informed and updated, so they are involved from the earliest stages of their child's life and can immediately start learning how to care for them. In some units, the dedication, sensitivity and professionalism of staff has meant that parents feel welcome and supported. This mum's experience should be a model for units across the country:

"The child I am describing was my second child as my son had died a year earlier on the same unit. The staff and the consultant... were absolutely outstanding and made myself and my husband feel better. For example the [consultant] came to see me and ask which cot I wanted [my daughter] to go in, due to where [my son] had died. This may seem trivial to other people, but this meant the world to me."

However, because of the staffing pressures that many units operate under, nurses and doctors simply can't spend as much time as they would like to with parents. Nurses in particular play a vital role in providing support and reassurance and helping families adjust to their new role of caring for a sick or premature baby. It is recognised that written information can help parents to take in often complex information about treatments and procedures. We are encouraged that 79 per cent of parents received Bliss leaflets. However, this cannot compensate for the human touch. One mother's thoughts illustrate this:

"The staff were... usually very busy. I did feel that at times, asking questions seemed almost an intrusion in their schedule as they had so many other jobs/feeds/nappy changes/meds to sort out."

The staffing shortages are beginning to become all too apparent. Eight per cent of parents, unprompted, mentioned issues over a lack of staff. Here is a selection:

"Staff fantastic and dedicated, just not enough of them."

"I was very impressed with the staff but their workload was completely unreasonable and there wasn't the provision for one to one care, even when our baby was in Intensive Care."

"At one point one of the nursing staff was in tears because she felt so compromised by the poor levels of staffing – which were impinging on the extent to which she could do her job professionally."

With no staff available to explain often complex clinical procedures, parents can sometimes feel disengaged from their baby's care, to the point where they struggle to feel like parents at all.

"I often felt like my baby wasn't mine, not enough was explained to me. It seemed the neonatal nurses were understaffed with too much to do. On the whole most of the staff were friendly enough but did not have enough time to talk to you about your baby."

Transfers

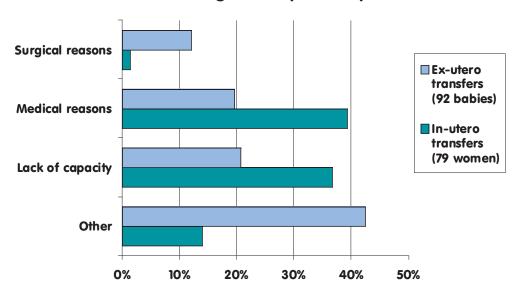
Staff shortages not only have an impact upon the 'softer' side of care, but they also mean that babies may have to be transferred to other units if staffed cots are not available at their home unit.

Twenty four per cent of parents reported being transferred before birth (in-utero) and 28 per cent had their baby transferred after birth (ex-utero). Thirty seven per cent of parents who were transferred before birth and 21 per cent of parents whose babies were transferred after birth reported that they were moved because a lack of capacity. The most common reason given for an ex-utero transfer was "other". This includes when a baby is moved back to a unit closer to home. While there are genuine reasons why babies may need to be moved, transfers that happen because of a lack of staffed cots are inappropriate and should not be occurring.

These transfers can be extremely disruptive to family life and can cause huge financial and practical difficulties. Over a third (36 per cent) of parents whose babies were transferred reported that the distance they had to travel to visit their child was 30 miles or more. Of parents who had twins or triplets, 29 per cent had their babies cared for separately in different hospitals. If handled incorrectly, these transfers can be a frightening and confusing time:

"First hospital was chaos, and extremely disconcerting. No cots, no information. We spent eight hours waiting (in a waiting room or ambulance) for them to find a cot. Little info at this time, very scared parents to be."

What reasons were given for your baby's transfer?



When it is necessary to transfer a baby, it is essential that parents are given information about the unit their baby is destined for. In our survey, 43 per cent of parents whose babies were transferred received no such information before their baby was moved.

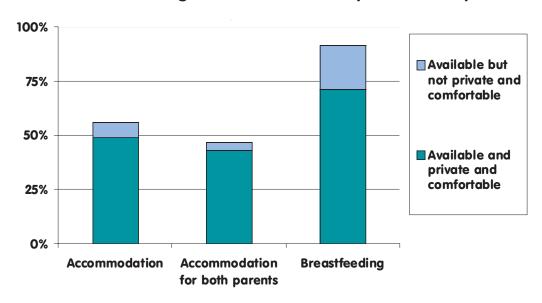
Financial impact

The financial cost of having a baby in neonatal care can be significant. Research has shown there are strong links between low income, social deprivation and having a low birthweight baby² so the financial impact can be even greater for some families. Bliss research last year estimated that having a premature or sick baby costs parents an extra £189 per week on average during the time their baby is in hospital. The main costs are travelling to and from hospital to visit their baby, buying food away from home, the cost of lost earnings and car park charges. It is important that, at the very least, hospitals offer advice and support on how parents can cope financially at this difficult time.

Facilities for parents

The chart below illustrates the facilities provided for parents. Accommodation for both parents was available for less than half of parents surveyed. While this is a clear improvement on previous years, the importance of accommodation for both parents should not be underestimated. Mothers often tell Bliss that their worries were made worse by the fact that their partner could not be with them at this difficult time.

Were the following facilities available to you to use as parents?



Breastfeeding

A mother's breast milk is the best possible source of food for all new babies, but for premature and sick infants, it is particularly valuable for providing protection against infections, promoting development and encouraging the bond between mother and baby.

While provision for breastfeeding and expressing breast milk is provided to most mothers, one in five parents said that they were not private and comfortable. Recent Bliss research found that even though most knew about the benefits, 38 per cent of mothers surveyed did not breastfeed.³ In another study, the National Neonatal Audit Programme found that 41 per cent of babies born before 33 weeks did not receive any of their mother's milk.⁴ Some parents of premature babies find it difficult to breastfeed their child. These data clearly show that more needs to be done to support them.



Skin to skin contact

Evidence suggests that the benefits of skin to skin care include increased attachment between mother and baby, stabilised breathing and heart rate, improved sleep and feeding patterns, and easier expression of breast milk.⁵ It is encouraging that 82 per cent of parents were able to have skin to skin contact with their baby, and that 79 per cent were actively offered it. Experts recommend that skin to skin contact last for at least half an hour. Our survey revealed that only around one in three mums (35 per cent) were able to have this amount of time on a regular basis.

Going home with your baby

Half of parents told Bliss that they had no contact with their health visitor before their baby was discharged. Over half said that there was no plan agreed in advance with the community health workers. While a baby is on the neonatal unit, the parents are surrounded by a whole team of professionals caring for them and their baby. When they finally get to go home, it can be a daunting and sometimes frightening experience. One in five parents said they did not feel adequately prepared for going home with their baby. In this situation, community neonatal nurses are worth their weight in gold as they can help prepare a baby for earlier discharge from hospital and help the parents adjust to being the main carers.

Survey of UK hospitals

In April 2008, Bliss sent a survey under the Freedom of Information Act 2000 to all 213 hospitals with a neonatal unit in the UK.⁶ We received information from 91 per cent of units.

Although progress is being made, there is still a desperate shortage of specialist nurses, and units are under enormous pressure. Here we look at the picture of neonatal care across the UK. Accompanying this report is a more detailed briefing on neonatal care in your UK country. This can be found in the pocket at the front of this report and online at www.bliss.org.uk/babyreport2008

Staffing

Approximately 22,000 babies were admitted for neonatal Intensive Care in the UK in 2007. This is roughly one baby every 24 minutes. In 2001, the British Association of Perinatal Medicine (BAPM) published clinical standards which set out how babies should be cared for in Intensive Care. These standards (see box below) set out how many babies a nurse should care for at one time.

British Association of Perinatal Medicine minimum nursing levels:7

- Intensive Care: At least one nurse to one baby
- High Dependency Care: At least one nurse to two babies
- Special Care: At least one nurse to four babies

A recent study observed nurses working in level 3 units to assess how much time they spent looking after babies in Intensive Care. It found that a nurse spends on average 56 minutes in every hour providing direct care for the baby. However, it was clear that some babies required more care than could be provided by a single nurse, and that two nurses sometimes needed to spend the majority of their time caring for just one baby. This provides clear evidence that the one to one nurse to baby ratio, a minimum in Intensive Care, is still an essential standard to implement. The study also concluded that babies in all levels of care need more of a nurse's time than the last time such a study was conducted in 1993.

One to one nursing care is the standard in children's and adult Intensive Care. It is only in neonatal care that lower standards are regarded as acceptable. In neonatal Intensive Care, it is common for a nurse to have to look after two babies.

Neonatal nurses tell Bliss that their work is immensely rewarding. However, staff shortages inevitably make their work more difficult and stressful. In our previous report *Too little, too late?* (2007) we looked at the shortage of nurses compared to the number of cots across the UK. This year we have looked at whether hospitals had enough nurses to meet the care needs of the babies they admitted. Using information that hospitals gave us about the care they provided to babies, we can work out the minimum number of nursing staff, according to the BAPM standards, that are needed to provide that care. We can then compare that with the number of nurses the hospitals actually employed. The table below shows the results. All figures refer to whole time equivalents.*

	Total number of nurses		Total number of consultants		Number of units meeting BAPM standards		Shortage of nurses in those units not meeting BAPM standard	
	2006	2007	2006	2007	2006	2007	2006	2007
Level 1 (31 units)	413	433	38	38	4	5	209	204
Level 2 (70 units)	1,494	1,513	119	134	13	13	647	625
Level 3 (50 units)	2,636	2,738	206	217	11	14	592	492
Units that did not supply a designation (12 units)	328	334	37	36	3	3	56	47
Total (163 units)	4,871	5,017	400	425	31	35	1,504	1,368

In the 163 units that gave us information about the care they provided and their nursing staff, 35 (21 per cent) had enough nursing staff to provide the minimum nursing levels to the babies they admitted in 2007. In the whole of the UK, there are only fourteen of the most specialised Level 3 units that told us they can meet the minimum standard. This demonstrates that it is possible to achieve this and other units now need to follow this good example.

Clearly there has been some progress in increasing the number of neonatal nurses, which is to be welcomed. However, there is still a long way to go. A long-term strategy is needed to recruit and train neonatal nurses. If the increase in nurses that occurred between 2006 and 2007 could be doubled next year and then maintained at the same rate each year, the staffing standards could be fully met by 2015. This, however, does not take into account the likely increase in demand.⁸

Assuming the staffing levels in the 163 units are representative of all units, there was a shortage of around 1,700 qualified neonatal nurses for the babies that needed neonatal care in 2007 across the UK.

In the 186 units that gave us information about their nursing staff, there was a total increase of 160 nurses between 2006 and 2007. Scaled up for the whole of the UK, we estimate that there is a total neonatal nursing staff of around 6,500. To allow for sudden peaks in activity, experts recommend that units should aim to operate at 70 per cent capacity. When this recommendation is taken into account, we estimate there needs to be at least 9,000 neonatal nurses to provide the care that babies need.

^{*} This is a unit of measure that is equal to one filled, full time annual salaried position.

There is a similar shortage on the number of doctors who specialise in neonatal care. One level 3 unit and 25 level 2 units said they have no dedicated neonatal consultant. In these cases, paediatric consultants with a special interest in neonatal care provide cover, but several units said they were unable to recruit a neonatal consultant to a vacancy. With the imminent implementation of the European Working Time Directive, limiting doctors to a 48 hour maximum working week, and the increasing impact of Modernising Medical Careers on junior doctor rotas in some hospitals, this is a significant cause for concern.

Occupancy

Every unit can only safely accept a certain number of babies. This depends on the number of cots and the number of staff they have. If the unit becomes full, they will always provide emergency care to any new baby that needs it. However, they then try and find an appropriately staffed cot in another unit. Once the baby has been stabilised and is well enough to travel, they are transferred to another hospital.

Fifty five per cent of units said that they had to close to new admissions at some point between 1 April and 1 September 2007. As in the year before, units in 2007 were forced to close to new admissions for an average total of over two weeks over a five month period (the equivalent of just over five weeks over a year). One in five was forced to close for a total of three weeks or more (the equivalent of seven weeks over a year). Seven units were closed for a total of three months or more (the equivalent of over seven months over a year).

It is impossible to plan when babies needing emergency care will be delivered. So the Department of Health and BAPM recommend that units operate at an average occupancy of 70 per cent. This enables them to deal with sudden peaks of activity and maintain a manageable workload. In 2007, only one in five of the most specialised level 3 units met this recommendation. What's more, almost a third of all units went to 100 per cent capacity or more at some time. The majority of these were level 3 units. This trend is getting gradually worse, and more level 2 units are also reaching 100 per cent capacity.

Transfers

Units try to avoid transferring babies long distances, but unfortunately this is still an all too common occurrence. Units told us that, between 1 April and 1 September 2007, they had to transfer 491 babies because of a lack of capacity. This is around three babies every day on average. In the same period, 35 per cent of in-utero transfers (367 women) and 36 per cent of ex-utero transfers (1,336 babies) were to a unit outside the local area. The impact on the family, both financial and emotional, cannot be underestimated, and the previous chapter outlines some parents' experiences of these difficult circumstances.

Examples of caring for families

Neonatal care is a rapidly evolving field. As well as important medical advances, doctors and nurses are continually developing new ideas about practical steps to improve the care for babies and their families. Here is a small selection of them.

Helen Mullen, Neonatal Sister, Neonatal Intensive Care Unit, Lancashire Teaching Hospitals, Preston:

"On our neonatal unit, we have a special 'bubble room'. Inside there's a comfy rocking chair and a large bubble lamp that casts different colours across the room. There's a large mirror on the wall. It provides gentle stimulation to our babies in a relaxed atmosphere but also offers parents the opportunity to spend short periods of time alone with their new baby. For many, the mirror on the wall will be the first time they have seen themselves holding their new son or daughter."

Parents often tell Bliss that they don't feel like a mum or dad until they have left the unfamiliar setting of the unit. The 'bubble room' in Preston is an excellent example of staff taking steps to help parents adjust to their new role as mum or dad of a vulnerable baby.

Chrissie Israel, Neonatal Development Specialist Nurse, Southmead Hospital, Bristol:

"In many hospitals parents are asked to leave the unit during ward rounds. This is so that no parent overhears the confidential information about someone else's baby. At Southmead's, we encourage mums to bring or borrow an iPod that they can plug into. This means that they can stay having a skin to skin kangaroo cuddle or breastfeeding in peace without overhearing anything."

Skin to skin contact has benefits for both mother and baby. These include making expressing breast milk easier. Because mothers of babies in neonatal care often find it difficult to express breast milk, anything that can be done to help should be encouraged.

Clare Gonella, Neonatal Nurse, The Queen Mother's Hospital, Glasgow:

"One of our staff members has a valuable artistic flair and she creates a variety of very special items that are given to parents. One example is a beautifully crafted baby scrapbook. Parents can use this to display photos and record special milestones in their baby's life. The tremendous thing to acknowledge is that all of these items are created in the staff member's own time!"

Diaries and scrapbooks are a great way of helping a family to see their time on a neonatal unit as a journey. They can be used to celebrate and commemorate little milestones like the first cuddle, the first suck or the first bath. Parents often say that a very premature baby can take two steps forward and then four steps back, so it's important to recognise and appreciate their gradual progress.

Conclusions

This report highlights the value of the care that doctors, nurses and other neonatal staff provide on a daily basis for our most vulnerable babies. The enormous gratitude and warmth that parents feel towards the doctors, nurses and other health professionals is clear. However, a significant number of parents felt that more could have been done to inform and involve them in the care of their child. Staffing shortages, inadequate facilities and too many inappropriate transfers mean that while babies often receive excellent care, their parents can feel neglected or in the way when they are at their most emotionally vulnerable.

Neonatal staff are being forced to work in situations where they are overstretched and the unit is understaffed. Bliss is often asked by nurses and doctors to speak out about the lack of progress they experience on the ward.

This is the fourth Bliss Baby Report to identify neonatal care services that are in significant difficulties. The difference this year is that it is not only Bliss who are calling for action to address these problems. Official bodies both inside and outside the NHS are setting action plans and objectives. The under-resourcing of neonatal care services has now gone on for far too long. The Governments, National Assemblies and the NHS need to be committed in the long term to building these services up, not just to the minimum standards, but to the best possible standards.

An essential step is to recognise that babies have the same right to nursing care as anyone else who needs Intensive Care. It has been stated repeatedly that one to one nursing care in intensive should be the minimum. Anything less than this is not acceptable.

Please see the individual briefings accompanying this report for comments and recommendations for each UK country. These can be found in the pocket at the front of this report and online at www.bliss.org.uk/babyreport2008

Methodology

Bliss sent a request for information under the Freedom of Information Act 2000 to all 213 hospitals with a neonatal unit in the UK. Four surgical units were excluded because they have a different operational structure to other units. The three units on the Isle of Man, Jersey and Guernsey were also excluded. We received a response from 196 units (92 per cent). Two units declined to provide information.

We asked 16 questions about the number of admissions, their designation, transfers, staffing and occupancy. The figures quoted in this report have therefore been supplied by the hospitals themselves. No one question was answered by every unit, but most units answered most questions. The number of responses per question ranged from 119 to 191. The average was 173.

Bliss fully supports the work of healthcare professionals. Many of them approach Bliss asking us to speak out about the problems that exist in their profession. Our motivation for conducting this report is to publicise both the problems and some possible solutions to improve care services for babies and their parents but also to improve working conditions for healthcare staff. We cannot conduct this work without the support of healthcare professionals and we are very grateful for their co-operation.

To calculate the number of nurses needed to care for the babies admitted in 2007, we used the number of care days for each level of care that units gave us. We divided this number by 365 to get an average number of occupied cots for each level of care in each unit. We then applied the following formula to calculate the number of nurses needed according the BAPM 2001 standard:

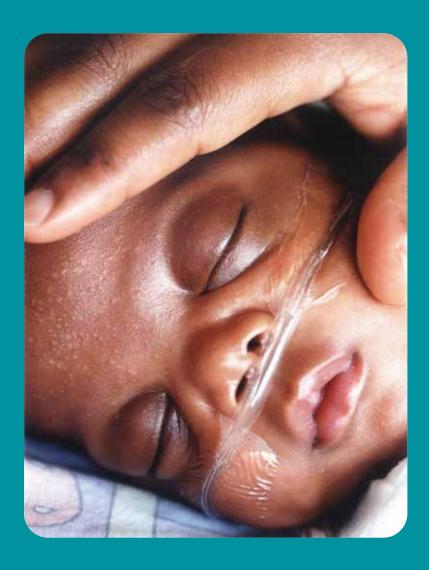
((number of Intensive Care cots) + (number of High Dependency cots/2) + (number of Special Care cots/4) +1) x 5.75

In June 2008, Bliss posted a survey on our website asking parents to tell us about their experience of having a baby in neonatal care. We asked 34 questions including one open question inviting people to give their overall impression of neonatal care. Four hundred and eighty four people completed the survey. We excluded 153 of these either because their baby had received neonatal care outside the UK or before 2006. Of the remaining 331 responses, 280 had received care in England, 27 in Scotland, 20 in Wales and four in Northern Ireland. Twenty nine per cent had their baby in 2006, 44 per cent in 2007 and 27 per cent in 2008.

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- 2 Dickute et al "Maternal socio-economic factors and the risk of low birthweight in Lithuania" (2004).
- 3 Breastfeeding and expressing for a sick or premature baby An overview of 500 women's experiences, Bliss (2008).
- 4 Annual Report, National Neonatal Audit Programme (2008).
- 5 Bliss literature review of carers' experiences of developmental care (unpublished at the time of writing).
- 6 The neonatal units on the Isle of Man, Jersey and Guernsey and neonatal surgical units are not included in this survey. Three units declined to provide information.
- 7 Standards for hospitals providing neonatal intensive and high dependency care (Second edition) British Association of Perinatal Medicine, December 2001.
- 8 For detailed estimates and possible strategies for meeting future need see Simon Lenton's work: *Modelling the Future II Reconfiguration and workforce estimates*, Royal College of Paediatrics and Child Health (2008).





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Bliss is a member of **Language Line**, the telephone interpreting service, which has access to qualified interpreters in over 170 languages.

Blisstext - text messaging advice line. Text your name to 07800 00 8100. Online parent messageboard **www.blissmessage board.org.uk**

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