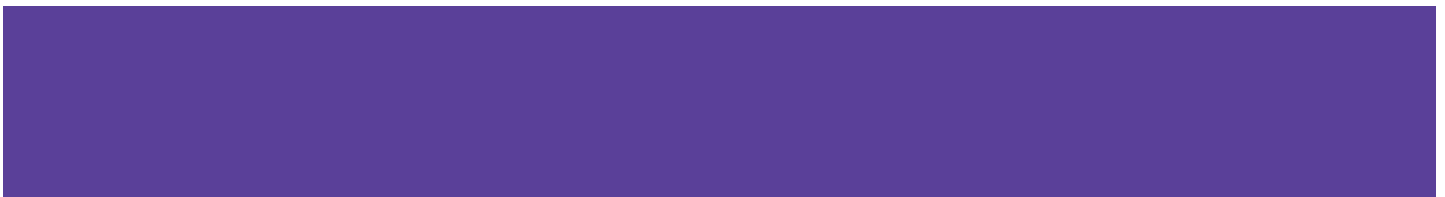


Counting the cots

Neonatal care services in London

May 2006



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Chair's Foreword



Around 11,000 babies in London each year need the extra care provided in neonatal units, and this number is growing. London's neonatal units are therefore under increasing pressure.

Our report is concerned with how neonatal care services are coping with the increasing demand put upon them. We also wanted to explore parents' views about the care their babies received and how they were involved in the care of their babies.

We found that neonatal care services are generally working well but that increased pressure means that units are operating at a much higher level of capacity than is advisable. Neonatal units in London are understaffed. Some experts suggest that more than 500 extra nurses are needed in the capital, and many units are struggling to recruit enough consultants and junior doctors. Three hospitals told us that they had been forced to close neonatal cots because they did not have enough staff available to keep them open.

Parents' experiences of neonatal care vary widely. Although all the parents we spoke to were happy with the medical care their baby had received, they felt that more could be done to involve parents in their baby's care, to keep them informed about their baby's progress and give them information about the unit and what to expect. There was also a lack of facilities for parents at many units.

However, we also found many reasons to be positive. We found examples of good practice in parent involvement, such as units employing parent support workers to provide help and advice to parents at a difficult time. Recent government investment has helped set up five local networks in London to co-ordinate neonatal services, and has helped set up a dedicated transport service which has made moving babies between hospitals quicker, easier and safer. Perhaps most importantly, the extra money means that London has 77 more neonatal cots in 2006 than it had in 2002. However, these extra cots will only help reduce the capacity problems if they are accompanied by a significant investment in staffing.

Our report makes recommendations that we believe will ensure neonatal care services in London continue to improve, and cope with the increasing demands put upon them.

A handwritten signature in black ink, reading 'J. McCartney'.

Joanne McCartney, AM
Chair, Health and Public Services Committee

The Health and Public Services Committee membership & terms of reference

The membership and terms of reference for the Health and Public Services Committee were agreed at the meeting of the Assembly on 11 May 2005.

Joanne McCartney	Chair	Labour
Elizabeth Howlett	Deputy Chair	Conservative
Angie Bray		Conservative
Jennette Arnold		Labour
Geoff Pope		Liberal Democrat
Darren Johnson		Green

Terms of reference of the Health and Public Services Committee

1. To examine and report from time to time on -
 - The strategies, policies and actions of the Mayor and the Functional Bodies
 - Matters of importance to Greater London as they relate to the promotion of health in London and the provision of services to the public (other than those falling within the remit of other committees of the Assembly) and the performance of utilities in London.
2. To liaise, as appropriate, with the London Health Commission when considering its scrutiny programme.
3. To consider health matters on request from another standing committee and report its opinion to that standing committee.
4. To take into account in its deliberations the cross cutting themes of: the achievement of sustainable development in the United Kingdom; and the promotion of opportunity.
5. To respond on behalf of the Assembly to consultations and similar processes when within its terms of reference.

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Comments on the findings and recommendations of this report are welcomed. Any comments will be considered as part of the review and evaluation of this investigation.

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Executive Summary

Nationally some 10% of babies are born premature, very sick, or very small and need some kind of specialist care. In London this means that every year around 11,000 babies are admitted to one of the capital's neonatal units.

London's neonatal units are under increasing pressure. The birth rate in London is increasing because of the high number of women of childbearing age living in the capital. Recent medical advances have increased the survival rate of premature babies, meaning that doctors routinely plan premature births. Many of the risk factors for having premature or low birthweight babies are at particularly high levels in London's communities. These risk factors include poor nutrition, poor housing, having fertility treatment or having a sexually transmitted infection or disease.

The London Assembly's Health and Public Services Committee has therefore been investigating how well London's neonatal units are meeting the increasing demand on their service.

The Committee found that overall, neonatal care services in London are working well and coping admirably with the increasing pressure put upon them. London is a centre of expertise in neonatal care, with many of the leading neonatal staff based in the capital. Neonatal units are staffed by committed and hard working doctors and nurses, with support from other key health professionals such as dieticians and physiotherapists. All the parents we spoke to were happy with the medical care their babies had received. We also found several examples of good practice for involving parents in neonatal care, including community neonatal nursing teams, who work with parents to help them get their babies home more quickly.

The Department of Health has made major investments in neonatal care over the past few years, which is welcomed by the Committee. This investment led to the development of five London neonatal networks to co-ordinate and oversee local service delivery. It helped set up a Neonatal Transfer Service to move babies from one hospital to another. The money has also helped units increase their capacity: there are 12% more number neonatal cots in the capital now than there were four years ago.

However, evidence we have received indicates that there are still problems with neonatal care services in London:

- London's neonatal units are operating with fewer than recommended numbers of nurses or consultants, due to insufficient funding and difficulties recruiting and retaining staff.
- Too many babies have to be cared for a long way from their homes, because local units do not have the capacity to admit them. However, neonatal cots at several units cannot be used because of a lack of staff.
- Funding is sometimes slow to get through to units and networks, delaying improvements to services.

Furthermore, the Committee heard many examples of staff failing to communicate effectively with parents. Parents gave examples of staff failing to update them on their baby's progress. Many parents said that they were not encouraged to get properly involved in caring for their baby. As a result, they found taking their baby home a daunting prospect, not helped by the fact that some were only offered minimal home support. The experience of having a baby in a neonatal unit is always a stressful one for parents, but not being kept informed and involved can make the situation much worse. We hope that the recommendations made in this report will go some way to improving that situation.

Summary of Recommendations

Recommendation 1

Managers of neonatal units that have staff retention problems should consider what more they could do to encourage staff to stay, including offering more flexible working policies and offering staff more personal development opportunities. Network managers could support this work by collecting and disseminating examples of good practice in staff retention.

Recommendation 2

The Department of Health should increase funding of neonatal care to enable units to meet BAPM staffing level standards for nursing and medical staff. The Department of Health also needs to clarify whether and when investment will be made available to enable these standards to be met.

Recommendation 3

The five London Neonatal Network Managers should monitor the money allocated by the Department of Health to neonatal care services, and ensure it reaches frontline services from PCTs in a timely manner.

Recommendation 4

All networks should consider how they could improve joint working between neonatal care services and related health services, notably maternity and community health services. Neonatal networks should consider whether to develop into perinatal networks, to facilitate this joint working.

Recommendation 5

A member of staff on each unit should be designated as parent liaison manager to act as an advocate for parents, manage parent feedback and provide information and support to parents.

Recommendation 6

Neonatal network managers should produce a good practice guide on parent involvement, family facilities and discharge support with regard to the examples outlined in section 6 of this report. Network managers should monitor the implementation of this good practice, and should disseminate examples of innovative practice within and between networks.

Recommendation 7

The Neonatal Transfer Service should review procedures for parents accompanying their baby on transfers, and establish protocols for parental accompaniment on both elective and emergency transfers.

Follow up

We will contact all relevant organisations in London to inform them of our recommendations, and ask for their implementation. We will review progress on implementing the recommendations at least six months after the publication of this report.

1. Introduction

- 1.1 A baby girl was born at 27 weeks. The local hospital where she was due to be born did not have the specialised staff or facilities to deal with such a young baby so they transferred her to a specialist intensive care unit in central London. After two weeks she was transferred back to her local hospital, where she became seriously ill with a life threatening condition. Again, the local hospital did not have the facilities or specialists to deal with this so they tried to transfer her to a specialist intensive care unit in London. However, no London units had space, so she had to be transferred to a hospital in Cambridge, where she stayed for five months. After this, she was transferred to a specialist hospital in London, before coming home around seven months after she had been born. The traumatic events around and after her birth were extremely difficult for her and her family, not least for her older sister who had to spend five months shuttling between London, where she stayed with relatives, and Cambridge, where her parents had moved to be near her baby sister¹.
- 1.2 10 percent of babies need some kind of specialist care because they are premature, very small or very sick. In London this means around 11,000 babies born each year or 30 babies born each day are admitted to one of the capital's neonatal units, where they can receive the specialised medical care they need.²
- 1.3 Neonatal units in London are under increasing pressure. The birth rate in the capital is increasing, Londoners have more low birthweight babies than average and medical advances mean more planned premature births.
- 1.4 The London Assembly's Health and Public Services Committee therefore decided to investigate how well London's neonatal units are meeting the increasing demand on their service. The Committee looked into the adequacy of facilities at the units, staffing, how services are managed and funded and how babies are moved between hospitals. The Committee also looked at parents' experiences of neonatal care, including how effectively they were involved in their babies' care and treatment.

How we conducted this investigation

- 1.5 We received written information from a wide range of organisations and individuals, which enabled us to understand the main issues in neonatal care. Responses to our call for evidence were received from organisations including hospital trusts, neonatal and perinatal networks, BLISS (the premature baby charity), and The Royal College of Nursing. We also received written evidence from a number of parents whose babies needed neonatal care. A full list of people who sent in written information can be found attached as appendix A.
- 1.6 We visited neonatal units at St. Thomas' Hospital and the Homerton Hospital, which provided excellent opportunities to meet professionals working in the field, and to observe how units operate. We also visited the Emergency Bed Services (EBS) Operations Centre, where we met staff from EBS and the Neonatal Transfer Service, to find out how they find available cots for babies and organise transfers between units.
- 1.7 We held two meetings; one with professionals working in the field, and one with parents whose babies needed neonatal care. These meetings allowed us to investigate

¹ This story is based on the written submission sent in by Shelley, parent

² Office for National Statistics, 'Birth Statistics – Review of the Registrar General on births and patterns of family building in England and Wales 2004', Series FM1 No.33, 2005

in more depth the issues facing staff working in neonatal care, and parents. Details of the meetings can be found in appendix A.

Levels of Neonatal Care

- 1.8 There are three different levels of neonatal care based on the complexity and severity of a baby's needs. Babies may need different levels of care at different times during their stay in neonatal units. All babies will be at level one before they are allowed home.
- Level One – Special Care. For any baby whose parents could not reasonably be expected to look after them at home. This includes babies who need their breathing or heart rates continuously monitored, need extra oxygen, need to be tube fed, and babies recovering from more specialist care.
 - Level Two – High Dependency. For babies who need more than level one care but do not fulfil any of the criteria for level three. This includes babies weighing less than 1,000g who do not need intensive care, babies who need intravenous feeding, and babies with apnoea (breathing problems) requiring stimulation.
 - Level Three – Intensive Care. For babies with the most severe or complex care needs, including babies who need respiratory support (ventilation); babies under 29 weeks gestational age, and babies who require or are recovering from major surgery.³

³ Written submission from NHS London Specialised Commissioning Group p.3-4; and 'Facts and Figures' BLISS 2005 available at www.bliss.org.uk

2. The London Context

Growing pressure on London's neonatal units

- 2.1 The pressure on London's neonatal units is increasing for a number of reasons.
- 2.2 The birth rate in London is increasing. There were 8 percent more live births in 2004 than in 2001⁴. London currently has a higher number of births per 1,000 population than any other region in England and Wales⁵. The main reason for this is that London's population has a higher than average proportion of women of childbearing age.
- 2.3 A higher proportion of babies born in the capital have a low birthweight compared to national averages, because of high levels of risk factors in London's population. In 2004, 8.2 percent of babies born in London weighed 2,500g or less compared to an England and Wales average of 7.6 percent⁶. Low birthweight babies are far more likely to need neonatal care than other babies. The likelihood of having a baby that needs neonatal care is linked to several risk factors, many of which are particularly prevalent in London's population. Older mothers (aged 35+), women who have had fertility treatment, women who have a poor diet, who live in poor housing or who have sexually transmitted diseases and infections⁷ are all more likely to have babies who need neonatal care⁸. Many of these risk factors are being considered as part of wider initiatives to tackle health inequalities. The Committee therefore welcomes the role of the Mayor and the London Health Commission in leading partnership work to tackle health inequalities, including many of the risk factors mentioned above.
- 2.4 Department of Health figures show that babies of mothers from Pakistan, Caribbean countries and parts of Africa have much higher than average rates of neonatal mortality⁹. This information suggests that babies of mothers from these ethnic groups are more likely to need neonatal care services than other babies, making ethnicity another risk factor in neonatal services. London's population contains a higher proportion of people from Asian Pakistani, Black Caribbean and Black African ethnic groups than the national average, which adds to the pressure on London's neonatal units¹⁰.
- 2.5 Medical advances mean that premature babies now have a much higher chance of survival. Twenty years ago only 20 percent of babies weighing less than 1,000g at birth survived, whereas now 80 percent survive¹¹. These medical advances mean that medical staff now plan many pre-term births, putting extra pressure on neonatal units.

⁴ Office for National Statistics 'Population Trends 120', 2005; and Office for National Statistics, 'Birth Statistics – Review of the Registrar General on births and patterns of family building in England and Wales 2001', Series FM1 No.30, 2002

⁵ Office for National Statistics 'Population Trends 120', 2005

⁶ Office for National Statistics, 'Health Statistics Quarterly 27' 2005- Babies weighing 2,500g or less are classified as low birthweight babies

⁷ The London Assembly's Health and Public Services Committee has published two relevant reports on sexually transmitted infections and diseases in London: "Improving young people's sexual health" 2005; and "Living with the virus – a scrutiny of HIV services in London" (2004). Both these reports are available from www.london.gov.uk

⁸ Written submission from NHS London Specialised Commissioning Group, p.31 and written submission from BLISS, p.2-3

⁹ Office for National Statistics 'Health Statistics Quarterly 28' 2005 -Report on infant and perinatal mortality by social and biological factors 2004'

¹⁰ 'Census 2001', Office for National Statistics; 'ONS Population Estimates by Ethnic Group, 2001-2003' February 2006, GLA Data Management and Analysis Group

¹¹ Written submission from BLISS, p.7

- 2.6 London is a centre of expertise in neonatal care, in areas such as surgery, cardiology and urology. This means that babies from across the country are brought to London units for these kinds of specialist treatment¹².

Neonatal networks and units in London

- 2.7 There are currently 29 Neonatal Units across the capital, plus a unit at Great Ormond Street Hospital covering neonatal surgery and other specialised services.
- 2.8 In 2003, five neonatal networks were set up in South West, South East, North West, North East and North Central London to co-ordinate and manage neonatal care. These networks were developed following national and regional reviews of neonatal care that recommended units should be organised into 'managed clinical networks'. In each network there is a range of Neonatal Units providing different levels of care. Every network has at least one unit providing level three (Intensive Care) facilities, and several units offering lower levels of care.
- 2.9 The purpose of the networks is to provide equitable access to care for babies, as near as possible to their homes. Therefore, all networks have a target of caring for 95 percent of local babies within their network. Parents have told us that distance is a crucial issue for them, because if their baby is in a unit far from home, this can limit the number of visits they can make, can cause them to incur huge travelling costs, and can cause real problems with childcare if they have other children¹³.
- 2.10 There is widespread support for the development of neonatal networks in London.
*'We believe this (network system) is the best way families can receive the best care in their local area and outcomes for babies will be improved. Due to its dense urban population, London is particularly suited to a network system.'*¹⁴
- 2.11 However, the network system has also presented extra challenges. A representative of the Royal College of Nursing has said that the network system has resulted in a smaller number of units offering level 3 care, meaning that more transfers are now needed, increasing the pressure on transport services¹⁵. Staff in the EBS Operations Centre have said that the network target of caring for 95 percent of babies within the network means that units may be tempted to reserve cots for local babies. EBS staff believe that this reservation system could be making it more difficult for them to find available cots.¹⁶

¹² Written submission from South East London Neonatal Network p.2

¹³ Written submission from Shelley (a parent) p.1, and Transcript of meeting with parents whose babies needed neonatal care, 8th March 2006, p.4, p.26

¹⁴ Written submission from BLISS, the premature baby charity p.4

¹⁵ Written submission from the Royal College of Nursing, p.1

¹⁶ Notes of visit to Emergency Bed Services on 2nd March 2006, p.2

3. The capacity of neonatal facilities

Cot occupancy levels

- 3.1 Neonatal units across London are regularly operating at higher than recommended occupancy levels. The British Association of Perinatal Medicine (BAPM)¹⁷ and BLISS recommend that neonatal units should operate at an average cot occupancy level of 70 percent, so they can respond effectively to changing admission demands and maintain safety.¹⁸ Units across the capital have reported that they regularly operate at or above 90 percent occupancy¹⁹, and two have told us that they have operated beyond 100 percent capacity²⁰. These high occupancy levels create stressful and cramped working environments for neonatal staff.
- 3.2 High occupancy levels can compromise infection control procedures, and can therefore lead to higher levels of hospital acquired infections such as MRSA²¹.
- 3.3 There is also high demand for neonatal surgery, cardiology and urology cots in London. Demand for cots on units that offer these specialist interventions is often particularly high and hard to predict because these units receive babies from across the country²². Staff at these units have to prioritise the admission of babies needing these specialist interventions over the admission of other babies, which can make it even more difficult to find cots for local babies²³.
- 3.4 High occupancy levels on neonatal units mean that it is far more difficult to find an available neonatal intensive care cot than other types of intensive care bed. The Emergency Bed Service helps hospital staff find suitable, available beds for their patients. During 2004 on average, EBS staff found paediatric intensive care cots were available at four times more hospitals than neonatal intensive care cots²⁴.
- 3.5 High occupancy levels mean networks are struggling to meet their target of providing care for 95% of babies within their local network²⁵. One hospital reported that in 2005, 40 percent of the babies transferred out of their unit had to be sent out of their local network, because of a lack of space locally²⁶.
- 3.6 We have had reports of London babies needing to be transferred to Luton and Cambridge, because of a lack of capacity in London's units. Long-distance transfers make it expensive, stressful and time consuming for parents to visit their babies, especially if they have other children to care for. Sometimes, because units are full, or

¹⁷ British Association of Perinatal Medicine – 'Standards for Hospitals providing neonatal intensive and high dependency care' Dec 2001 available at www.bapm-london.org

¹⁸ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.4 available at www.london.gov.uk/assembly/health_ps/index.jsp

¹⁹ Written submissions from the South East London Neonatal Network, Barts and the London NHS Trust, St George's Healthcare NHS Trust, and North Central London Perinatal Network.

²⁰ The Princess Royal University Hospital in Bromley reported a occupancy level of 122 percent for their neonatal unit during 2004. The average occupancy rate for medical neonatal cots at the Royal London Hospital between 2003 and 2006 was 89-101%. Sources: Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.4 and written submission from Barts and the London NHS Trust, p.2

²¹ 'Improving Patient Care By Reducing the Risk of Hospital Acquired Infection: a progress report', Comptroller and Auditor General, July 2004, National Audit Office; 'MRSA in London', an investigation by Elizabeth Howlett on behalf of the London Assembly's Health and Public Services Committee, October 2005.

²² Written submission from the South East Neonatal Network, p.2

²³ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.9

²⁴ Neonatal Transfer Service for London, Kent, Surrey and Sussex Annual Report 2004/5

²⁵ Written submission from the North East London Perinatal Network p.6; Neonatal Transfer Service Annual Report 2004/5

²⁶ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.4

overcrowded, mothers go into labour in one hospital without knowing whether their babies will need to be transferred to another hospital as soon as they are born:

'When I was in labour, they were trying to transfer us out because there were five babies too many in the unit... There was an atmosphere of panic; like we just cannot have another baby here... I was left on my own in labour for an hour and a half, because people were so busy trying to find where I was going to go... That was a nightmare, then it continued after she was born. They really were not sure whether she would be able to stay.' Toni, parent²⁷.

'[The consultant told me] "Last week we were phoning Glasgow and Lille [France] for cots"... I just thought, "oh my God"... during the night, I was getting people coming in saying, "We are going to send one [of your twins] to Brighton, one to Lewisham"... I could not imagine how difficult that would be.' Yasmin, parent²⁸

- 3.7 There tends to be very little space between cots on neonatal units. As a result, confidentiality and privacy can be hard to maintain, particularly when occupancy levels are high.
- 3.8 Despite these capacity problems, parents can be reassured that their babies will receive good quality care in London's units. All the parents we spoke to were happy with the medical care their babies had received. Furthermore, neonatal care services in London are staffed by hard working, skilled personnel, including many of the leading experts in neonatal care.

Cot numbers

- 3.9 The number of neonatal cots has increased over the past few years. London had 651 cots at the start of 2006, compared to 574 in 2002, - an increase of 12 percent. The ratio of neonatal cots across the networks is being changed with an increase in the proportion of level one cots. This increase in level one cot numbers should mean staff can transfer babies out of level three cots more quickly. As a result, level three cot blocking (a baby staying in a level three cot longer than necessary because of a lack of alternatives) should be reduced, making units more efficient. Table 1 shows in detail how cot numbers in London have changed between 2002 and 2006, and predicted cot numbers for 2012.

Table 1: Neonatal cot numbers in London for 2002, 2006 and 2012²⁹

Type of cot	2002 Cot Numbers	2006 Cot Numbers	2012 Proposed Cot Numbers ³⁰
Level 1 Special Care	304	412	439
Level 2 High Dependency	94	91	117
Level 3 Intensive Care	176	148	143
Totals	574	651	699

- 3.10 This overall increase in cot numbers should help tackle the problem of high occupancy levels and reduce the numbers of long-distance transfers. However, this increase will only make neonatal services better able to cope with increasing demands if it is accompanied by significant increases in staffing.

²⁷ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.4

²⁸ *ibid*, p.10

²⁹ Written submission from NHS London Specialised Commissioning Group, p.41-43

³⁰ The 2012 figures are calculated using the Department of Health Neonatal Toolkit and current birth rate predictions. These predicted cot numbers are recalculated when new birth rate information becomes available

4 Staffing

Staffing Levels

- 4.1 Cots are standing empty in units across the capital because of a major lack of neonatal staff. One hospital has reported that six of their 15 neonatal cots cannot be used because they do not have enough funding to recruit the staff needed to open them. Two other units have both reported that five of their cot spaces cannot currently be used.³¹ Therefore, at least 16 cot spaces in London are out of use because there are not enough staff available to open them.
- 4.2 There are no Government standards for neonatal staffing levels. However, the British Association of Perinatal Medicine (BAPM) has developed standards that have been endorsed by the Royal College of Obstetricians and Gynaecologists, and are supported by BLISS and staff at neonatal units. These standards include:
- Babies in intensive care (level 3) – a nurse with a neonatal qualification should be responsible for no more than one baby
 - Babies requiring high dependency care (level 2) – a nurse should be responsible for no more than two babies
 - Babies requiring special care (level 1) – a nurse should be responsible for no more than four babies
 - Level 3 neonatal units should be staffed by seven full time equivalent consultants³²
- 4.3 Despite aspirations to meet these BAPM standards, none of the 29 neonatal units in London are currently able to³³. In fact, many units are operating with far lower levels of nursing and medical staff. The unit at St. George's Hospital has reported that it would need around 42 more nurses and two more consultants to meet BAPM standards.
- 4.4 Interestingly, Royal College of Nursing representatives have reported that babies in high dependency care often need more intensive support than babies in level three care, which the BAPM standards do not take into account. Level three babies who are heavily sedated and being ventilated often need less nursing support than level two babies who do not have a secure airway and are only minimally sedated. Because they are only minimally sedated they move around more, making the equipment in the incubator less secure.³⁴ It may therefore be worthwhile considering whether babies in high dependency care should also receive one to one nursing.

Nursing Staff

- 4.5 The most pressing staffing issue is a severe lack of neonatal nurses. BLISS estimates that 540 more nurses are needed in London to meet BAPM staffing standards³⁵, and

³¹ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.4; Written submission from St. George's Healthcare NHS Trust, p.2; Notes of visit to St. Thomas' Hospital Neonatal Unit, 26th January 2006

³² British Association of Perinatal Medicine – 'Standards for Hospitals providing neonatal intensive and high dependency care' Dec 2001, p.4-8; available at www.bapm.org

³³ Written submissions from hospitals and units including: the North Central London Neonatal Network, p.5; South East London Neonatal Network, p.2; Barts and the London NHS Trust p.2; Epsom and St. Helier University Hospitals, p.1; St. George's Healthcare Trust, p.2, St. Mary's NHS Trust, p.4-5.

³⁴ Written submission from the Royal College of Nursing, p. 2

³⁵ Written submission from BLISS, p.8

neonatal networks endorse this estimate. Hospital and network representatives have said that the lack of nursing staff is partly due to a lack of revenue funding for nursing positions, but is also because units have major difficulties recruiting and retaining nursing staff.

- 4.6 It is very difficult for hospitals in inner London to recruit and retain more senior, experienced nurses. According to a representative of the Royal College of Nursing, experienced nurses are put off by the high cost of living in inner London, a relatively low Higher Cost Award (similar to London Weighting), and limited salary increases for more senior staff:

*'Living is more expensive in London and the pay differential is not that much different. A band 6 [experienced nurse] living in Wales would be pretty well off, but a band 6 here is going to be badly off.'*³⁶

- 4.7 In contrast to inner London, a representative from an outer London unit reported more difficulties with recruiting and retaining junior nurses. This is because junior nurses find it too expensive to live locally, whereas more senior nursing staff tend to have family ties to the area, and have been settled there for several years³⁷.
- 4.8 Other factors contribute to difficulties recruiting and retaining staff. These include long commuting times, poor public transport services for shift workers, stressful working conditions and inadequate or expensive hospital parking.
- 4.9 A representative of the Royal College of Nursing suggested incentives that could encourage experienced nurses to stay in London. These incentives included increased Higher Cost Awards, reimbursement of the congestion charge, and free tube and bus travel in London (which Metropolitan Police Officers receive)³⁸. St Thomas' Hospital is therefore overseeing the development of affordable housing units at a location a mile from the hospital, to enable nurses to live close to the hospital, reducing commuting times and hopefully encouraging staff retention. The Department of Health and Hospital Trusts should assess staff's housing needs on a regular basis, and review whether their plans are meeting these needs.
- 4.10 Interestingly, staff at the Homerton Perinatal Unit stated they had only very few problems recruiting and retaining nursing staff. They believed this was partly because of a drive to recruit nurses from overseas, and partly because of the unit's supportive approach to staff's work/life balance, and to their professional development. Recently, for example, the unit's management has enabled more flexible working practices, by allowing nurses to choose whether to work fewer long shifts or more short shifts. The management has also supported one nurse to train as a professional counsellor, and she now works part time as a neonatal nurse, and part-time as a parent counsellor on the neonatal unit.

Recommendation 1

Managers of neonatal units that have staff retention problems should consider what more they could do to encourage staff to stay, including offering more flexible working policies and offering staff more personal development opportunities. Network managers could support this work by collecting and disseminating examples of good practice in staff retention.

³⁶ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.22

³⁷ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.24-5

³⁸ *ibid*, p.26

- 4.11 Some units employ community neonatal nurses who support parents to prepare for their baby's discharge and to be able to look after their babies at home, meaning that that babies can get home more quickly. Community neonatal nurses are discussed further in section 6.

Medical Staff

- 4.12 There is a lack of junior neonatal doctors at some units in the capital. These units find it difficult to recruit junior doctors because of the perceived stress and unsocial hours of neonatal care, and an increase in litigation.³⁹
- 4.13 Units across London are operating with lower than BAPM recommended numbers of consultants. One network has reported that some of its units are unable to provide 24-hour senior medical cover, meaning that complicated emergency procedures often have to be undertaken by more junior doctors⁴⁰. Furthermore, the lack of junior doctors at some units can mean consultants taking on more junior tasks as well as their own, adding to their workloads.⁴¹
- 4.14 The elements of the European Working Time Directive that come into force in 2009 will further limit the number of hours junior doctors and consultants can work, which means that more will need to be recruited to cover the same number of hours.

Other staff

- 4.15 Staffs such as dieticians, counsellors and physiotherapists are integral members of the multidisciplinary teams that deliver care to babies on neonatal units. They also provide vital support parents and babies after discharge. The services they provide can reduce the length of the baby's hospital stay, and can also prevent later hospital admissions. According to neonatal units, funding for these staff is not always factored into units' forward plans⁴². **Ensuring there are adequate resources for these staff is something that should always be factored into government funding for units as well as networks' resource plans.**

Increasing staff numbers

- 4.16 The Committee believes that funding of neonatal care services in London should be increased to enable BAPM staffing level standards to be met. As well as helping to relieve overstretched staff, increasing staffing numbers will also enable units to open extra cots that they have not been able to use because there are not enough staff available for these to be used.

³⁹ Written submissions from St. Mary's NHS Trust, p.5; Barts and the London NHS Trust, p.3

⁴⁰ Written submission from North Central London Perinatal Network p.5

⁴¹ Written submissions from St. Mary's NHS Trust, p.5

⁴² Written submissions from Epsom and St Helier University Hospitals NHS Trust, p.2 and North Central London Perinatal Network

5. Funding and Managing Neonatal Care Services

How Neonatal Care is funded

- 5.1 The Department of Health announced a major investment in neonatal services in 2003 to help set up the networks and transport services and to improve facilities at neonatal units. The amount of money allocated to each network was based on the local birth rate, adjusted to take account of the proportion of low birth weight babies in the area. London received around £14,900,000 overall - about 21 percent of the national total.
- 5.2 Although this funding has made major differences to neonatal care services in London, several funding problems remain. Neonatal networks, units and BLISS agree that current funding allocations will not enable London units to meet the BAPM staffing levels outlined in section 4.2, or meet the recommended BAPM occupancy target of 70 percent. Representatives of the North Central London Network have stated that it would cost an extra £1,400,000 a year in staffing costs to achieve BAPM recommended nursing levels across their network⁴³. Furthermore, the Department of Health investment funding was only allocated for the financial years 2003/4 to 2005/6, and it is not yet clear whether neonatal care services will receive any extra investment after this date to enable further improvements to be made.

Recommendation 2

The Department of Health should increase funding of neonatal care to enable units to meet BAPM staffing level standards for nursing and medical staff. The Department of Health needs to clarify whether and when investment will be made available to enable these standards to be met.

- 5.3 Some units have informed us that they rely on charitable donations for a significant proportion of the new equipment they need:
- ‘For equipment... we rely on charitable donations and parents’ good will. However, this is not enough to provide the equipment required and to ensure that this is replaced and upgraded in a timely and necessary fashion’.*⁴⁴
- 5.4 We have received some evidence of money being slow to get to networks and units⁴⁵. A representative of one neonatal unit also stated that they felt the local PCTs had been very slow to pass on the money allocated to their unit.
- 5.5 Funding for neonatal intensive care services comes through a different stream to special care services. According to one consultant, this situation makes managing neonatal care more difficult and complicated than it needs to be⁴⁶. BLISS agrees with this position, and believes that all neonatal care services should be commissioned through the same system. They feel that this would make it easier for units to deal with issues such as cot blocking – where a baby has to stay in a level three cot when it no longer needs level three support, because of a lack of other cots⁴⁷.

⁴³ Written submission from North Central London Perinatal Network, p.5

⁴⁴ Written submission from Epsom and St. Helier University Hospitals NHS Trust.

⁴⁵ Representatives of the North Central London Network informed us that they had not received their capital budget from the Department of Health (via their local Strategic Health Authority) at the time they submitted written evidence, which was the 31st January 2006.⁴⁵

⁴⁶ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.29

⁴⁷ Written submission from BLISS, p.8

Recommendation 3

The five London Neonatal Network Managers should monitor the money allocated to neonatal care services, and ensure it reaches frontline services from PCTs in a timely and clearly accountable manner.

Managing Neonatal Care – Linking with other related services

- 5.6 Neonatal Care must be effectively coordinated with maternity care and community health services to ensure that mothers and babies receive a seamless, high quality service:

‘Even if current difficulties in neonatal services are resolved, failure to address the requirement to provide appropriate care and arrangements for mothers of babies who will require neonatal care will prevent delivery of the standard of care for families and babies to which we aspire’.⁴⁸

- 5.7 If neonatal units worked closely with maternity services to review and plan capacity, it would be easier to arrange in-utero transfers. In-utero transfers are currently harder to arrange because a bed for the mother and a cot for the baby need to be found at the same hospital. However, evidence shows that in-utero transfers are preferable because they are safer for the baby⁴⁹, and allow a mother and baby to be close to each other at all times.
- 5.8 One model for achieving closer joint working between neonatal care services and other related services is the development of perinatal networks. Perinatal networks have been set up in some areas of London instead of neonatal networks. Perinatal networks co-ordinate and oversee neonatal care services as well as other aspects of perinatal care, such as ongoing care for mother and baby after they have left hospital.

Recommendation 4

All networks should consider how they could improve joint working between neonatal care services and related health services, notably maternity and community health services. Neonatal networks should consider whether to develop into perinatal networks, to facilitate this joint working.

- 5.9 The Department of Health announced in April 2005 that from July 2005 the five London Strategic Health Authorities (SHAs) will be disbanded and will be replaced by one pan-London SHA. The pan-London SHA could have a positive impact in terms of best practice sharing and joint working across the networks. However, staff have told us that they hope that this new structure does not disrupt current arrangements for managing neonatal care including the five network structure, which they believe is working well.⁵⁰

⁴⁸ Written submission from North Central London Perinatal Network, p.2

⁴⁹ Several academic studies have shown in-utero transfers are safer than postnatal transfers, including Fowlie et al ‘Moving the preterm infant’, British Medical Journal 2004; 329: 904-906; and Chien et al ‘Improved outcomes of preterm infants when delivered in tertiary care services’, Obstetrics and Gynaecology, Vol. 98 No.2 August 2001

⁵⁰ Written submission from Barts and the London NHS Trust, Epsom and St Helier University Hospitals NHS Trust and North East London Perinatal Network.

6. Parent involvement

- 6.1 Parent involvement ranges from providing parents with information about the unit to engaging parents as members of a unit's management board. Parent involvement at neonatal units varies a great deal. There are many examples of good practice at London units, several of which are highlighted below. However, parents have also given us examples of staff failing to keep them up to date about their baby's progress, not encouraging them to get involved in their baby's care, and not giving them basic information about the units. The experience of having a baby in a neonatal unit is always a stressful one for parents, but not being kept informed and involved can make the situation much worse.

Information about the unit and their baby

- 6.2 Parents have told us that they need good practical information about the unit. They want details of how to get there by public transport, parking facilities, parent facilities, and any financial help they might be able to access for transport costs and accommodation. Information about the other hospitals in their network would also be useful. However, a recent BLISS survey found that a quarter of parents surveyed did not receive information about the unit their baby was on⁵¹. A number of parents we spoke to told us that they were not made aware of facilities at the unit such as parents' bedrooms. Parents have also told us that they need general information about why babies are admitted into neonatal units, what the equipment on the units does, and the kind of treatment their baby might receive. As one parent said:

"It was difficult to take in all the information/facts ... It would have made an enormous difference if the info had been given to me in writing. I could have then had time to read and absorb and then ask relevant questions." Pauline M, parent⁵²

Good practice – written information packs

Parent Information Guide that covers a range of subjects including breastfeeding, how neonatal units work and how to prepare for a baby being discharged. The pack also includes information about the unit, such as public transport links, parking facilities, and parent facilities.

Babies' care and treatment

- 6.3 Parents we spoke to said that unit staff were sometimes poor at keeping them up to date about their baby's treatment and progress. We heard several examples of hospital staff not even providing basic information to parents, such as telling them when their baby had been moved to a different part of the unit. As one parent told us:

'My baby was also moved without me being told. I went in, and my baby was not there. I thought- maybe she died. It is very shocking, especially if your baby is in intensive care, and it is quite touch and go.' Justine, parent and BLISS family support worker⁵³

⁵¹ BLISS, 'Special care for sick babies – choice or chance?' June 2005

⁵² Written submission by Pauline M, p.1

⁵³ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p. 17

- 6.4 Parents also want to be involved as much as possible in caring for their baby and in decisions about the treatment their baby receives. When Committee Members visited St. Thomas' Hospital, parents said that they are encouraged to be involved in ward rounds, which they welcomed⁵⁴. However, a number of parents have told us that in other units they were sent out of the room when ward rounds were taking place, missing opportunities to hear about their baby's progress and get involved in treatment decisions. Parents have said that they were worried about harming their baby by touching or picking them up. They felt that staff need to give them a lot of encouragement and guidance about how to touch, hold and care for their baby:

'Not only were we chucked out when the medics came round, but then if the nurses wanted to have their meeting, which is a separate time, you would be chucked out again. You waited hours to have your half an hour of cuddling your baby, which is important for bonding, and then they would chuck you out'.

Yasmin, parent⁵⁵

'You are asked to do some of the practical stuff, like the nappy-changing, but in my case I really did not get into that very much, because I needed a lot more help and encouragement to deal with all the – just all the wires and the paraphernalia. I was terrified that every time I picked her up the alarms would all go off'. Toni, parent⁵⁶

Good practice – involving parents in treatment and care

Developmental Care – The Winnicott Baby Unit at St Mary's Hospital practices developmental care, which takes the individual needs and situation of each baby into account during medical treatment and hospital care and involves their parents in direct care as much as possible. Specialists at the unit help parents learn how to care for and comfort their babies. Research shows that babies cared for under a Developmental Care charter get better more quickly, go home sooner and have fewer developmental difficulties than other babies.⁵⁷

Meeting the needs of London's diverse communities

- 6.5 Neonatal services in London need to meet the needs of all of the capital's diverse communities, including people whose first language is not English, people of different faiths and cultures, and disabled people.
- 6.6 Parents whose first language is not English, and parents who are deaf or hard of hearing may need language support services to help them understand what is happening with their baby, and get involved in care and in treatment decisions. However, a recent BLISS survey showed that nationally 20 percent of units did not have access to an interpreting service⁵⁸. We have heard examples of units relying on family members to provide interpreting services, which can interfere with confidentiality, and lead to confusion because the language used can be complex and technical. Other units have reported using hospital staff to provide interpreting services, which is clearly not always practical as it takes them away from their work. The lack of comprehensive language support services has meant that parents whose first language is not English are sometimes unclear what was happening to their baby⁵⁹. Therefore, the Committee believes that units should always use professional interpreting services rather than members of staff or parents.

⁵⁴ Notes of visit to St. Thomas' neonatal unit, 26th January 2006

⁵⁵ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.5

⁵⁶ *ibid*, p.5

⁵⁷ More information on developmental care can be found at www.winnicott.org.uk

⁵⁸ BLISS, 'Special care for sick babies – choice or chance?' June 2005 available at www.bliss.org.uk

⁵⁹ Written submission from BLISS, p.5

'[There was] an African lady ... whose child was very severely disabled. She could speak French, and yet every time we were in there [the neonatal unit], nobody could talk to her, apart from [my partner] who could speak French. I thought that was shocking'. Darren, parent⁶⁰

'The other thing is that the language issues are exacerbated by stress and fear... Having had to receive information about my daughter, you do not hear properly... If I experience that and English is my first language... the potential for misunderstanding is huge [for people whose first language isn't English]' Justine, parent and BLISS family support worker⁶¹

- 6.7 Language support services are particularly crucial in London due to the diversity of its population – with more than 300 different languages spoken in London's schools⁶². This diversity is added to by the millions of business visitors and tourists who come to London every year, many of whom will need to access medical services during their stay.

- 6.8 Unit staff also need to be aware of and supportive of people's cultural backgrounds and religious beliefs, and adapt their care accordingly:

'I remember there being a Spanish family ... There was lots of family around and lots of people taking over. This was because family support is what happens in these southern European countries. You could see some of the nurses getting a bit frustrated by that'. Pippa, parent⁶³

Good practice – language support services

At St. Thomas' Hospital and the Homerton Hospital, face-to-face interpreters are made available to all parents who need them. However, because face-to-face interpreters need to be booked in advance, and tend not to be available 24 hours a day, units should also use telephone interpretation services for emergencies/ out of hours interpreting needs.

Opportunities for parent feedback

- 6.9 Parents have told us that they would appreciate clear and simple ways of giving their views on the service they received. However, from the parents we have spoken to, it appears that asking parents for feedback is not a widespread practice:

'The baby cannot give feedback, so you do not ask for it. What is perhaps forgotten is that the parents' or family's experience is just as important... I do not think it is recognised that how parents feel about what has happened is in any sense interesting, because they are not the consumer'. Justine, parent and BLISS family support worker⁶⁴

- 6.10 Parents have made the following suggestions for how feedback could work best. They think that simple written methods, such as comments forms or satisfaction surveys would be the easiest way to get people's views. In terms of timing, parents would like some time to reflect on their experiences before being asked to give feedback. Some parents suggested that units should wait a year after babies are discharged from units before asking for parents' feedback. They have suggested that BLISS should be involved in developing the questions in the survey. Parents have also told us that they

⁶⁰ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.21

⁶¹ *ibid*, p.20

⁶² 'Planning for London's Growth' 2002, GLA, p.25

⁶³ *ibid* p.35

⁶⁴ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.33

feel it is crucial for their feedback to be acted upon⁶⁵. Network managers are best placed to monitor the way units use parent feedback.

- 6.11 Parents have told us that they did not want to complain about the service they received at neonatal units for two reasons. Firstly, all the parents we spoke to were grateful for the care their babies received at the units and therefore did not feel they should complain. Secondly, parents did not want to get into confrontational situations with the medical and nursing staff who were caring for their babies. Kingston Hospital employs a parent liaison worker at its neonatal unit to advise and support parents. Parents are able to make complaints and give feedback to this liaison worker, who is a step away from the care of their baby, and acts as a parents' advocate⁶⁶.

Recommendation 5

A member of staff on each unit should be designated as parent liaison manager to act as an advocate for parents, manage parent feedback and provide information and support to parents.

Good practice – parent feedback

In 2004, the North Central London Perinatal Network conducted a satisfaction survey in all its units. Parents on the network's user group developed and led the work on the survey, and an independent researcher analysed the findings. The survey covered subjects such as staff communication, parents' facilities and support given to parents to help them bond with and care for their baby. Language interpreting services were offered to help parents who needed them. Following the survey all hospital trusts were asked to produce action plans to tackle areas of concern. Progress on this is being followed up by the network's clinical lead.

Parent representation on management boards

- 6.13 Parents are now involved in all five networks' management boards as user representatives. Parent representatives also have input into management teams at some hospital trusts. Parent involvement in management boards is an important way of giving parents an opportunity to get directly involved in designing and reviewing neonatal services, including networks' structure and functions.

Good practice – parent involvement on network boards

In order for their involvement to be meaningful, parents who are acting as user representatives on network boards should be given training so that they can understand how trusts, networks and units operate. Parents should also be given handbooks to back up this training, including a glossary of technical terms and abbreviations. They should also be given simple, clear summaries of any changes in the NHS and how these will affect neonatal care services.

Parent and Family Facilities at Neonatal Units

- 6.14 It is often difficult to find space for a mother and baby at the same hospital because of overcrowding on labour, postnatal and neonatal wards. It is generally agreed that in-utero (pre birth) transfers of both mother and baby are safer than postnatal baby

⁶⁵ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.32-33

⁶⁶ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.22-23,27,33

transfers⁶⁷, but overcrowded maternity wards mean that in-utero transfers are even more difficult to arrange than postnatal transfers.

- 6.15 Mothers of babies who need neonatal care are usually placed on general postnatal wards, because of a lack of separate facilities. This can be very stressful for mothers, because of the lack of privacy, high noise levels and because they are surrounded by mothers who have their babies with them. As one mother told us:

'I was in a room with five other women, all of whom had their baby beside them, while I hadn't even seen mine'. Toni, a parent⁶⁸

- 6.16 The facilities available for parents and other family members vary widely from unit to unit. Most neonatal units have bedrooms for parents to stay in overnight if they need to, although at many units there are only one or two bedrooms, which is often not enough to meet demand⁶⁹.

- 6.17 The British Association of Perinatal Medicine (BAPM) developed guidance for the design of parent and family facilities in 2004. This guidance recommends that at every unit there should be:

- Double parents' bedrooms,
- A parents' sitting room that includes a children's play area for siblings, and an education area,
- A room for expressing breast milk,
- Breast milk storage facilities.⁷⁰

Good practice – family facilities at neonatal units

St. Thomas' Hospital Neonatal Unit has three double parents' bedrooms, a children's play area, and a breast milk bank. Private breastfeeding facilities are also available. Spiritual advisors representing all faiths are on hand to provide support to families who need them. Parents' views fed into the design of the refurbished unit.

Parking and transport costs

- 6.18 Parents have reported that high parking and public transport costs in London can be a major expense, and can lead to financial difficulties. Parents can apply to hospitals to get back their travel costs as part of the Government's Fares to Hospital Scheme, if they are on certain benefits and low incomes. However, many parents are not made aware of this scheme, or have difficulties with the complicated procedures involved in making a claim⁷¹. Furthermore, family members driving to visit their baby in hospitals within the congestion charge zone are also liable to pay the congestion charge, further adding to their travel expenses. It is therefore crucial that information about parking and transport services, and how to pay the congestion charge (if relevant), is included in parents' information packs.

⁶⁷ PW Fowlie et al 'Moving the preterm infant' British Medical Journal 2004; 329: 904-906

⁶⁸ Written submission by Toni, a parent, p.2

⁶⁹ Written submission from the North Central London Perinatal Network p.4

⁷⁰ 'Designing a Neonatal Unit – Report for the British Association for Perinatal Medicine', BAPM, 2004

⁷¹ Written submission from BLISS, p.6

Going home

- 6.19 Parents have told us that they found taking their babies home stressful. Some parents had not had enough time to get all the equipment and clothing their baby would need at home because they had spent all their spare time at the hospital. Some parents felt that they might not be able to care for their baby at home because of the baby's ongoing health needs, or because they hadn't been properly involved in the baby's care at the hospital. Once home, some parents also felt inadequately supported by health visitors who often have no knowledge or experience of working with babies who have been in neonatal units. One parent told us that the health visitor she had been allocated was not even made aware of the date for her baby's discharge.

'Suddenly you are thrust out to the community. Your baby can be perfectly well and healthy, but still you are confused...you just have these extra fears'. Pippa - parent⁷²

"The health visitors will come round, but when there are wires and things involved, they are not comfortable with it." Pauline M, parent⁷³

- 6.20 Parents have told us of some positive experiences they had with the discharge process. One parent told us that she was given a homecare emergency helpline number to call if she needed support between health visitor appointments. One parent told us that the unit her baby was on was flexible about her discharge date to allow her time to get all the equipment she needed. One parent told us that she was actively encouraged to spend at least one night with her baby in a special bedroom at the unit to get used to looking after him without staff support.

Good practice – supporting parents to take babies home

Some hospitals including St. George's Hospital and Kingston Hospital employ community neonatal nurses to help get babies home from the units more quickly. These community nurses work with parents at the hospital, helping them prepare for their baby's discharge. Once the baby has been discharged, the community nurses make regular home visits to support the parents and to check on the baby's progress, as well as being available on the phone if parents need their advice. This service has several benefits: it can reduce bed blocking on the units, it means that parents can have their baby home sooner, and reduces the stress for the baby of being in a hospital environment.

Recommendation 6

Neonatal network managers should produce a good practice guide on parent involvement, family facilities and discharge support with regard to the examples outlined in section 6 of this report. Network managers should monitor the implementation of this good practice, and should disseminate examples of innovative practice within and between networks.

⁷² Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.9

⁷³ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.19

7. Transferring Babies

The Neonatal Transfer Service

- 7.1 Since 2003, London has had a dedicated emergency Neonatal Transfer Service (NTS) to move babies from one neonatal unit to another. The London NTS conducted 561 transfers in 2004, which equates to approximately 11 a week. The London service has a dedicated team of medical, nursing and ambulance staff to conduct the transfers using specially adapted ambulances. Babies are moved because of high occupancy levels, or because they need a type of specialist care that isn't available in the hospital they are in. Because demand for the service has been so high, the NTS is currently considering whether to set up a second emergency transfer team. There are also separate NTS teams in Kent, Surrey and Sussex who work with the London team when necessary, for example if twins need to be transferred. The NTS is co-ordinated by the Emergency Bed Service (EBS) whose staff find available cots for transfers, and oversee the transfer process.
- 7.2 The NTS has made a big difference to emergency postnatal transfers. Before the NTS existed, transfers tended to be very time consuming to arrange. Unit staff had to transfer the babies taking them away from their work on the unit. Transfers had to take place in normal ambulances using units' equipment, which was often incompatible with ambulance equipment. Representatives of neonatal networks and units and BLISS agree that the NTS has made transfers better, quicker and simpler:
- 'It really is an emerging beacon of best practice, the transfer service. Although there are issues that are still to be resolved, I think it is something that London can be quite proud of.'*⁷⁴
- 7.3 At the beginning of 2006, the NTS started an elective transfer service where babies can be moved to a suitable unit closer to home, if space is available. As well as making travel times shorter for parents, the elective service should also help to reduce bed blocking on level three units, because babies are moved to level one or two units nearer their homes when possible. The NTS also hopes that the new elective transfer staff will be able to undertake extra emergency transfers, when emergency staff are busy.

Issues with transfers

- 7.4 Parents do not generally accompany their babies on emergency or elective transfers. There is space in the adapted ambulances for one parent to accompany their baby, but an NTS representative has said that they don't tend to allow parents in the ambulance for emergency transfers in case the baby needs emergency treatment, and staff therefore need extra space to move around freely. In addition, mothers who have recently given birth and have their own medical needs would not be able to travel in the NTS ambulance.⁷⁵
- 7.5 However, emergency interventions such as resuscitation are unlikely to be needed during elective transfers. NTS staff therefore agree that parents could accompany babies more regularly during elective transfers⁷⁶. A parent who spoke to us also felt it was unacceptable for parents to be prevented from travelling with their babies during any transfer because this was not the case with older patients:

⁷⁴ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.37

⁷⁵ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.42

⁷⁶ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.42

*'If your one-year-old got meningitis and was rushed off to hospital, you would not say - you are not allowed to travel in the ambulance. If your husband was having a cardiac arrest and needed to go to hospital, you wouldn't be told - you are not allowed to come in the ambulance. It does not follow through for me'. Yasmin, parent.*⁷⁷

Recommendation 7

The Neonatal Transfer Service should review procedures for parents accompanying their baby on transfers, and establish protocols for parental accompaniment on both elective and emergency transfers.

- 7.6 To find out which units have available cots for transfers, EBS staff ring round all units twice a day. As well as finding out how many cots are currently available, they also collect 'soft information' about the number of cots that are likely to become available in the next day or so.
- 7.7 There are plans to develop an online cot availability system as part of a new London-wide neonatal database, which could replace the ring-round system. However, EBS staff feel that moving to an online system could prove problematic, as already overstretched hospital staff would need to take on the responsibility of updating the database. Their previous experience of asking unit staff to update them electronically about cot availability has not proved successful.⁷⁸
- 7.8 The Committee welcomes the online cot availability database. However, committee members feel that it will be essential for every unit to have designated staff members with designated time during their shifts to update the information. It will also be essential for the online system to allow soft information to be collected such as the number of cots that are likely to become available in the next 24 hours.
- 7.9 Medical staff have suggested that the NTS may have increased the number of postnatal transfers at the expense of in-utero transfers, even though in-utero transfers are safer⁷⁹. The NTS has dedicated staff and equipment to conduct postnatal transfers, but there is no equivalent team or equipment for conducting in-utero transfers. Therefore, hospital staff may be more likely to opt for postnatal transfers because these will be easier to arrange, and will not require the deployment of a hospital's own staff⁸⁰. EBS statistics do indeed show that the number of in-utero transfer enquiries it receives has decreased since the NTS was introduced in autumn 2003.⁸¹ In-utero transfers may also have decreased because they require staff to find a mother's bed and a baby's cot in the same unit, which is often very difficult.
- Information on maternity ward bed availability should form part of the online cot availability database to make in-utero transfers easier to arrange.**

⁷⁷ Transcript of Meeting with parents whose babies needed neonatal care, 8th March 2006, p.12

⁷⁸ Site visit to EBS Operations Centre, 2nd March 2006.

⁷⁹ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.37-38.

Several academic studies have shown in-utero transfers are safer than postnatal transfers, including Fowlie et al 'Moving the preterm infant', British Medical Journal 2004; 329: 904-906; and Chien et al 'Improved outcomes of preterm infants when delivered in tertiary care services', Obstetrics and Gynaecology, Vol. 98 No.2 August 2001

⁸⁰ Transcript of Health and Public Services Committee meeting, 22nd February 2006, p.37-38

⁸¹ Presentation given by Graham Hayter at Site Visit to St. Thomas' Hospital, 26th January 2006

Appendix A- Evidence and visits

To obtain any of the evidence listed, please contact Susannah Drury, Scrutiny Manager: email susannah.drury@london.gov.uk or tel 020 7983 4947

Meetings to collect evidence

Committee members held two meetings to collect evidence: one with professionals on 22nd February 2006, and one with parents whose babies had been in neonatal units, on 8th March 2006. Transcripts of these meetings can be downloaded from www.london.gov.uk/assembly
Details of the participants at these meetings are listed below.

22nd February 2006 – Meeting with professionals

- Sue McLellen, Head of Specialised Commissioning, London Specialised Commissioning Group
- Rob Williams, Chief Executive, BLISS – the premature baby charity
- Claire Alexander Clinical Nurse Manager, at St Thomas’ Hospital Neonatal Unit and Royal College of Nursing Representative
- Shaun Walter, Consultant, Special Care Baby Unit Princess Royal University Hospital, Bromley
- Nandiran Ratnavel, Consultant, Neonatal Transfer Service
- Geraldine Hoban, Head of Specialised Commissioning, Croydon Primary Care Trust

8th March 2006 – Meeting with parents whose babies had been in neonatal care units

- 6 parents attended, as well as one parent who is also a family support worker at BLISS, the premature baby charity.

Visits

Committee members made three site visits to meet professionals working in neonatal care. Notes of all these visits can be made available on request from Susannah Drury (contact details above).

- 26th January 2006 – St. Thomas’ Hospital Neonatal Unit.
- 2nd March 2006 – the Emergency Bed Services.
- 21st March 2006 – the Homerton Hospital Perinatal Unit.

Written Evidence

Written submissions were received from 6 parents whose babies had been in neonatal care, and the following organisations:

- Barts and the London NHS Trust
- BLISS, the premature baby charity
- Epsom and St. Helier University Hospitals NHS Trust
- Homerton University Hospital NHS Trust
- Kingston Hospital NHS Trust
- London Borough of Sutton
- London Specialised Commissioning Group
- North Central London Perinatal Network
- North East London Perinatal Network
- The Royal College of Nursing
- South East London Neonatal Network
- South West London Strategic Health Authority
- St. George’s Healthcare NHS Trust
- St. Mary’s NHS Trust

Appendix B – Good practice for parent involvement

Written information packs

Parent Information Guide that covers a range of subjects including breastfeeding, how neonatal units work and how to prepare for a baby being discharged. The pack also includes information about the unit, such as public transport links, parking facilities, and parent facilities.

Informing and involving parents in treatment and care

Developmental Care – The Winnicott Baby Unit at St Mary's Hospital practices developmental care, which takes the individual needs and situation of each baby into account during medical treatment and hospital care and involves their parents in direct care as much as possible. Specialists at the unit help parents learn how to care for and comfort their babies. Research shows that babies cared for under a Developmental Care charter get better more quickly, go home sooner and have fewer developmental difficulties than other babies.

Language support services

At St. Thomas' Hospital and the Homerton Hospital, face-to-face interpreters are made available to all parents who need them. However, because face-to-face interpreters need to be booked in advance, and tend not to be available 24 hours a day, units should also use telephone interpretation services for emergencies/ out of hours interpreting needs.

Parent feedback

In 2004, the North Central London Perinatal Network conducted a satisfaction survey in all its units. Parents on the network's user group developed and led the work on the survey, and an independent researcher analysed the findings. The survey covered subjects such as staff communication, parents' facilities and support given to parents to help them bond with and care for their baby. Language interpreting services were offered to help parents who needed them. Following the survey all hospital trusts were asked to produce action plans to tackle areas of concern. Progress on this is being followed up by the network's clinical lead.

Parent involvement on network boards

In order for their involvement to be meaningful, parents who are acting as user representatives on network boards should be given training so that they can understand how trusts, networks and units operate. Parents should also be given handbooks to back up this training, including a glossary of technical terms and abbreviations. They should also be given simple, clear summaries of any changes in the NHS and how these will affect neonatal care services.

Family facilities at neonatal units

St. Thomas' Hospital Neonatal Unit has three double parents' bedrooms, a children's play area, and a breast milk bank. Private breastfeeding facilities are also available. Spiritual advisors representing all faiths are on hand to provide support to families who need them.

Supporting parents to take babies home

Some hospitals including St. George's Hospital and Kingston Hospital employ community neonatal nurses to help get babies home from the units more quickly. These community nurses work with parents at the hospital, helping them prepare for their baby's discharge. Once the babies have been discharged, the community nurses make regular home visits to support the parents and to check on the baby's progress, as well as being available on the phone if parents need their advice. This services has several benefits: it can reduce bed blocking on the units, it means that parents can have their baby home sooner, and reduces the stress for the baby of being in a hospital environment.

Appendix C: Orders and translation

How to order

For further information on this report or to order a copy, please contact Dale Langford, Committee Administrator, on 020 7983 4415 or email to dale.langford@london.gov.uk

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Large print, Braille or translations

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আপনি বা আপনার পরিচিত কেউ এ রিপোর্টের সারসর্ম ও প্রস্তাবের কপি বিনামূল্যে বড়ছাপা বা ব্রেইল, অথবা তাদের নিজের ভাষায় চাইলে 020 7983 4100 এ নাম্বারে ফোন করুন বা ই মেইল করুন এ ঠিকানায়:
assembly.translations@london.gov.uk

જો તમને કે તમે જાણતા હો તેવી કોઈ વ્યક્તિને, આ અહેવાલમાંથી કાર્યકારી સંક્ષેપ અને ભલામણોની નકલ મોટા અક્ષરોમાં છપાયેલી, બ્રેઈલમાં કે તેમની પોતાની ભાષામાં વિના મૂલ્યે જોઈતી હોય, તો કૃપા કરીને ફોન દ્વારા 020 7983 4100 ઉપર અમારો સંપર્ક કરો અથવા આ સહનામે ઈ-મેઈલ કરો assembly.translations@london.gov.uk

Se você, ou alguém de seu conhecimento, gostaria de ter uma cópia do sumário executivo e recomendações desse relatório em imprensa grande ou Braille, ou na sua língua, sem custo, favor nos contatar por telefone no número 020 7983 4100 ou email em assembly.translations@london.gov.uk

ਜੇ ਤੁਸੀਂ ਜਾਂ ਕੋਈ ਤੁਹਾਡਾ ਜਾਣ-ਪਛਾਣ ਵਾਲਾ ਇਸ ਰਿਪੋਰਟ ਦਾ ਅਗਜ਼ੈਕਟਿਵ ਸੁਮਾਰੀ ਅਤੇ ਸੁਝਾਵਾਂ ਦੀ ਨਕਲ ਵੱਡੇ ਅੱਖਰਾਂ ਵਿਚ, ਬ੍ਰੇਅਲ ਵਿਚ ਜਾਂ ਆਪਣੀ ਭਾਸ਼ਾ ਵਿਚ ਮੁਫਤ ਪ੍ਰਾਪਤ ਕਰਨਾ ਚਾਹੁੰਦਾ ਹੈ ਤਾਂ ਕ੍ਰਿਪਾ ਕਰਕੇ ਸਾਡੇ ਨਾਲ 020 7983 4100 ਤੇ ਟੈਲੀਫੋਨ ਰਾਹੀਂ ਸੰਪਰਕ ਕਰੋ ਜਾਂ assembly.translations@london.gov.uk ਤੇ ਸਾਡੀ ਈ-ਮੇਲ ਕਰੋ।

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Haddii adiga, ama qof aad taqaanid, uu doonaayo inuu ku helo koobi ah warbixinta oo kooban iyo talooyinka far waaweyn ama farta qofka indhaha la' loogu talagalay, ama luuqadooda, oo bilaash u ah, fadlan nagala soo xiriir telefoonkan 020 7983 4100 ama email-ka cinwaanku yahay assembly.translations@london.gov.uk

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