Background

Of the 33,000 babies born in Wales each year, approximately 3,800 are admitted to the 13 neonatal units in Wales. As the birth rate in Wales continues to rise, the number of babies needing this care will also increase. In 2007, 50 families in Wales contacted Bliss for support. This is almost four times the number who contacted us the previous year.

Review of neonatal care in Wales

The Welsh health service is currently undergoing a period of change and review, and neonatal care is no exception. In 2005, Health Commission Wales (HCW) announced a consultation on neonatal care and Bliss sat on the working group in an advisory capacity. The review suggested a number of important recommendations for improving care and access to neonatal services in Wales, including the creation of two clinically managed neonatal networks.

Unfortunately, the review was never published for consultation, and its recommendations were left unconsidered. The review estimated the cost of implementing its proposals at £10.4 million. This may have been a factor in the delays that the project has suffered. The review correctly identified the problems that existed in neonatal care in Wales and proposed sensible solutions. However, doctors and nurses have been frustrated that the review and the implementation of its recommendations stalled.

Earlier this year, the review was resurrected and circulated to clinicians and other stakeholders for consultation and comment. Alongside the renewed interest in the consultation, a set of standards for neonatal care was drawn up by the Children and Young People’s Specialised Services Project (CYPSSP). These standards are comprehensive and ambitious in their scope, and provide an excellent launch pad for improving neonatal care across Wales. They endorse and echo the British Association of Perinatal Medicine’s (BAPM) staffing standards, including units providing intensive care levels of one nurse to one baby. It is suggested that the CYPSSP standards are monitored and audited annually, a move that would make Wales an example for the rest of the UK.

While these positive developments provide an indication that improvements could be made, there is yet to be any tangible progress. Neonatal transport remains inadequate, units across Wales are still understaffed and there is no coordinated management of data. As the standards acknowledge, the current delivery of services is “unsustainable”, and there is a “significant shortage” of adequately trained neonatal nurses. The data we received from units this year underlines this. A major issue for Welsh neonatal care services is how often they need to send babies across the border to be cared for in neonatal units in England. This is clearly difficult for families, as they may face long distances to travel to visit their baby. It is also difficult for the hospitals to account for financial resources and to commission services. This difficulty is only likely to increase with the introduction of Payment by Results (PbR)² in English neonatal care expected in 2010/11, and the current changes in Welsh healthcare.
Specialised services across Wales are currently also undergoing a period of transition. There is uncertainty over the future of HCW, the body that commissions “high-cost, low-volume” care in Wales. It is vitally important that the current policy work and rhetoric around improving neonatal care is turned into action, and not lost in the current service reconfigurations.

Survey of neonatal units in Wales

In spring 2008, Bliss sent out a Freedom of Information request to every neonatal unit in the UK. The data returned to us provides us with a comprehensive picture of the care provided for sick and premature babies. In Wales, all 13 units responded to our survey.

Staffing

Hospitals told us that four more consultants were employed in neonatal units in 2007 compared to 2006. They also told us that there were a total of 382 neonatal nurses employed across Wales in 2007. This is seven more than in 2006 and marks a two per cent increase. When we look at the amount of care that babies needed in 2007, we can calculate, using the BAPM minimum nursing standards, how many nurses in total are needed across Wales to deliver that care. To maintain a manageable workload and to cope with sudden peaks in demand, experts recommend that neonatal units should aim to work at 70 per cent occupancy. To achieve this, we calculate that Wales needs a total neonatal nursing staff of around 500.

Occupancy

It is impossible to plan when babies needing emergency care will be delivered, and so experts recommend that units operate at an average occupancy of 70 per cent. This enables them to deal with the sudden peaks of activity that occur and maintain a manageable workload. The majority of Welsh neonatal units work above this level. Between 1 April and 1 September 2007, 55 per cent had an average occupancy above 70 per cent. On average, units in Wales are marginally less busy than units in other parts of the UK. However, in 2006, 25 per cent of units in Wales said they exceeded 100 per cent capacity at some point. In 2007, this figure increased to 38 per cent. This is further evidence that units are under increasing pressure. The chart below illustrates how many units exceed 70 per cent capacity on a monthly basis.
Closed to new admissions

The shortage of neonatal nurses combined with the high levels of activity means that many Welsh units are overstretched. If a unit becomes full, staff will always provide emergency care to any new baby that needs it. However, this means they may have to try and find an appropriately staffed cot in another unit to move the baby to. Between 1 April and 1 September 2007, 73 per cent of units said that they had to close at some point. They did this for an average total of fifteen days during these five months (just over five weeks in a whole year).

Transfers

Wales does not have a dedicated neonatal transport service and relies on ad hoc arrangements. This means that clinicians or nurses will often have to spend a considerable amount of time ringing around units to find an appropriately staffed cot. When the unit is already full, this takes up valuable time when vulnerable babies need to be cared for. When a transport is arranged, staff may have to leave their home unit to accompany the baby to the host unit. This stretches the unit even more at an already busy time. Units told us that between 1 April and 1 September 2007, 20 babies had to be transferred due to a lack of capacity. This equates to about 50 babies each year.

When a transfer does occur, it may not be to a unit close to where the parents live. Indeed, our data shows that 27 per cent of transfers went outside their local area or were across the border to England. The effect of these transfers on families is often overlooked, and only exacerbates the emotional, financial and practical difficulties that many new parents of premature and sick babies experience. What's more, when babies are transferred across the border to England, their care is provided by the NHS in England and arrangements for commissioning this care can become complicated. It also leads to the amount of care that Welsh babies need being underestimated.

The importance of good communication with and support for parents is underlined by the responses of Welsh families to our online parents' survey. The vast majority of parents had nothing but praise for the consultants, nurses and other health professionals that cared for their babies during an extremely stressful and emotionally taxing time. However, many had comments to make about the ‘softer’ side of care, for example breastfeeding:

‘[Care was] excellent, we were constantly updated on our baby’s care and kept fully informed, the only thing I found frustrating was the lack of support to help me breastfeed once my baby was off the tube feed. I felt the nurses were pushing me to give bottles to make their lives easier, I did persevere and with the help of the breastfeeding counsellor on the post natal ward successfully left hospital breastfeeding.’

Bliss often hears from parents that while the care their baby receives is of a high standard, medical and nursing staff rarely have time to answer their questions fully. This is a side-effect of the shortage of nurses; not only does it affect the care that babies receive, but also the communication that parents receive. This can further have an impact on how involved families feel in their child’s care.

Conclusion

Wales has the potential to develop an efficient neonatal service that delivers a high quality level of care to the most vulnerable babies and their families. There are encouraging developments with the renewed interest in the HCW review, and the standards drawn up by CYPSSP are the most ambitious and comprehensive in the UK. However, a note of caution should be sounded; as yet, none of these have been put into action, and neonatal care in Wales remains the poor relation of its UK counterparts. With no dedicated transport system and no network structure in place, neonatal care in Wales is in urgent need of change. Furthermore, it is significantly understaffed and most units frequently operate above recommended capacity levels; a 31 per cent increase in nursing staffing is needed to reach BAPM standards. While there is good reason for optimism, action and investment are urgently needed to turn these hopes into reality.
Recommendations

- Neonatal care must be provided 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.

- The Welsh Assembly and Health Boards need to fully support, fund and implement the recommendations of the HCW review and CYPSSP standards.

- The Welsh Assembly, in conjunction with Health Boards, must draw up action plans to tackle the drastic shortage of qualified neonatal nurses.

- 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.

- Round-the-clock access to dedicated neonatal transport services must be available to all units in Wales including, where appropriate, cross-border transfers.

- Bliss leaflets and other information for parents to be made available to families in all units across Wales.

References

2 This is a relatively recent DH initiative intended to link the allocation of funding for healthcare with the actual activity that hospitals carry out. More information is available here: www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/NHSFinancialReforms/DH_077259