Health, Wellbeing and Local Government Committee

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Bliss response to the Health, Wellbeing and Local Government Committee's inquiry into neonatal care

for babies born too soon, too small, too sick

March 2010

1. Introduction

Bliss is the UK charity that cares for premature and sick babies. For thirty years Bliss has been dedicated to ensuring that these babies survive and go on to have the best possible quality of life. We provide practical and emotional support to families during an extremely difficult time, so they can give the best care to their babies. Our specialist study days and training supports doctors and nurses to develop their skills and we fund research to improve the care of all sick and premature babies. We also raise awareness of the issues and campaign for improvements to services to ensure special care babies have the best possible start in life.

Bliss welcomes the investment and commitment shown by the Welsh Assembly Government for improving neonatal services in recent years. However progress has been slow has stalled a number of occasions, and real change has yet to be seen in the care that special care babies and their families receive.

We welcome the opportunity to respond to this inquiry.

2. Summary

Approximately 4,000 babies were admitted to neonatal care in Wales in 2008, which was equal to 1 in 9 babies born. With a growing birth rate, this number looks set to increase year upon year.

Yet many units are significantly understaffed and frequently operate above recommended capacity levels. In Bliss' 2008 Baby Report, Baby Steps to Better Care, we found that a 31 per cent increase in nurse staffing is needed to meet recommended standards.

Neonatal services have undergone 12 reviews in Wales since Bliss was founded in 1979. These were conducted by a range of governmental and parliamentary bodies, professional organisations, and Bliss itself. Each documented the failures in the system and recommended action to remedy these problems. However, as yet, not one report has had their recommendations fully implemented.

The Welsh Assembly Government has made some welcome commitments to improve neonatal services, but there are still a number of challenges which remain to be addressed before these can be fully realised.

3. A Neonatal Network and Transfer Service for Wales

3.1 Bliss welcomes the £2m per annum investment announced by the Welsh Assembly Government in October 2008 to develop a neonatal network and transfer service in Wales. . Bliss was a stakeholder involved in the development of the business case setting out how this service should be delivered, and we were pleased this plan was accepted by the Minister for Health and Social Services, Edwina Hart AM, in December last year. The business case recommended:

Introducing a neonatal transport service with two different methods of delivery: one in the south and one in the north of Wales. The service will operate 12 hours a day.

Specialist neonatal services should be concentrated in three centres in the south and one in the north.

Recruitment to begin for additional neonatal consultants and neonatal nurses.

A single neonatal database enabling the standardised collection of data across Wales.

If fully implemented, this will significantly improve the care that babies and their families receive.

3.2 However, as stated above, the £2 million per annum investment only provides for a 12-hour transport service which will operate from 9am to 9pm every day. While this represents a significant improvement on the existing service, it means that babies born in the middle of the night will continue to rely on ad hoc arrangements which take neonatal nurses and doctors off busy units, putting already stretched services under pressure. Nurses and doctors on duty in the units will be relied upon to travel with mothers and babies requiring transfers during the night. The 2009 Wales Audit Office report, "Maternity Services, "concluded that providing neonatal transfers in this way "depletes the available resources and is unsatisfactory". It should be noted that neonatal transport services across

England and Scotland are almost uniformly provided on a 24/7 basis.

3.3 Bliss acknowledges the considerable challenges involved in introducing a separate neonatal transfer service, even one working only 12 hours a day, particularly with regards to staffing. There is a critical shortage of trained neonatal nurses and doctors in Wales, and recruiting staff to the transport service risks taking experienced staff off neonatal units. Please see Section 5 of this response for more information about staffing issues within neonatal services.

3.4. Despite these challenges a 24 hour transport service should be the goal. A press release issued by the Welsh Assembly Government on 7 December 2009, announcing Ministerial sign off of the above business plan, stated that the transfer service:

"will operate 12 hours a day in the first instance, with planned progress towards a 24-hour service in the future as staff resources are developed."

However the business plan does not set out how or when this will be achieved, and we are not aware of the existence of any other plans detailing how this will be increased to a 24/7 service. A recent answer to a Welsh Assembly Question indicated that any expansion of the transfer service will be down to the local NHS:

Mick Bates (Montgomeryshire): How will the increase in the neonatal transport service from 12 hours to 24 hours be funded. (WAQ55678)

Edwina Hart: As a result of recommendations from the neonatal expert group a 12 hour Neonatal Retrieval Service is being funded. Any further extension will be a matter for the Health Boards and the Welsh Health Specialised Services Committee to consider.

3.5 Recommendation: We urge the Welsh Assembly Government to provide the leadership and funding necessary to develop the workforce and run a 24-hour service as soon possible. This is the standard for transport services in Scotland and England. Special care babies in Wales deserve no less.

4. All Wales Neonatal Standards

4.1 In 2005, Health Commission Wales (HCW) announced a consultation on neonatal care. Bliss was involved in an advisory capacity in a working group to develop proposals for this review. However the review, which outlined a number of important recommendations for improving neonatal services in Wales, was never published for consultation and its recommendations were, for some time left unconsidered. It estimated the cost of implementing its proposals at £10.4 million, which is likely to have been a factor in the delays that the project suffered.

4.3 Also in 2005, a set of standards for neonatal care drawn up by the Welsh Assembly Government's Children and Young People's Specialised Services Project, was circulated for consultation. A further three years passed before the "All Wales Neonatal Standards", was published in December 2008. Despite the delay, the Standards present an ambitious vision for services for special care babies and their families, to be achieved over a ten-year period. They are highly comprehensive in their scope and, if fully implemented, will make a huge difference to neonatal services in Wales. The standards acknowledged that there is a "crisis in the current service" and that neonatal units in Wales "are grossly under-resourced and therefore inefficient".

4.4 The standards set out that care should be provided in a coordinated network of neonatal units and that a dedicated transport service with specially trained staff should be in place at all times in all areas of Wales. The funding that has been provided to date will go a long way to meeting these two standards, however further resources are clearly required to meet the standard for a 24-hour neonatal transport service, as explained in section 3.

4.5 The All Wales Neonatal Standards also endorse the British Association of Perinatal Medicine's (BAPM) own standards on staffing levels in neonatal units which state that all babies in intensive care should have access to a dedicated nurse for their care at all times; nurses in high dependency care should be caring for no more than two babies at any one time; and nurses in special care should be responsible for the care of no more than four babies at any one time. The standards also state that appropriately trained doctors are available to all units at all times. Staffing concerns are explained in more detail in section 5.

4.6 Other key standards include:

support services including nutritional support, physiotherapy, and speech and language therapy are readily available

appropriate cots and equipment are in place for babies who need high dependency and intensive care

breastfeeding is actively encouraged and supported in the unit

support services are available when needed from a range of professionals, including social workers, bereavement counsellors, breastfeeding support staff, psychologists and translators

resources are available for parent training.

4.7 While we welcome the All Wales Neonatal Standards, we are concerned about the degree to which they are actually having an impact on services. The standards document sets out that:

"Standards will be monitored and audited annually as part of the MCN (Managed Clinical Network) arrangements and will include audit of training, practice and compliance of pathways, protocols and agreed outcomes."

However although 15 months has passed since the standards were published, progress towards implementation has yet to be assessed as the neonatal network in not yet up and running.

4.8 Recommendation: We urge the Welsh Assembly Government to ensure that these services are audited against these standards without delay, and that this is repeated annually to ensure they are implemented fully across Wales. Consideration should be given to the establishment of an online assessment tool to enable the network to measure progress, such as that in place to monitor implementation of the National Service Framework for Children, Young People and Maternity Service in Wales.

5. Staffing

5.1 In spring 2008, Bliss sent out a Freedom of Information request to every neonatal unit in Wales. The information we received, from all of the 13 units, showed that 382 neonatal nurses were employed in 2007. However according to information provided about the level of unit and the number of nurses they have we calculated that 500 nurses were actually needed across Wales to meet the BAPM nurse staffing standards. This meant that a 31 per cent increase in nurses is required to provide the standard of care that babies in Wales need. The disparity between the number of nurses needed and those currently working in neonatal care is highly concerning, and with the increase in the birth rate and ageing nurse workforce, this is likely to worsen over time.

5.2 There is a fundamental inequality in the way our most vulnerable babies are cared for. While children and adults in intensive care receive a minimum of one nurse dedicated to their care, babies do not. Significant funding is needed to recruit, retain and train the neonatal nursing workforce in Wales to meet the BAPM and All Wales Neonatal Standards.

5.3 There is strong evidence that providing one to one nursing for babies in intensive care improves their outcomes. One study found that providing this standard of care for intensive care babies was associated with a decrease in risk-adjusted mortality by 48 per cent*. Furthermore, a shortage of staff can have a major impact on the care that premature and sick babies and their families receive. This includes babies being transferred long distances to find a staffed cot, sometimes even out of Wales; units sometimes having to close to new admissions; and staff not having enough time to involve parents in the care of their baby (detailed in section 7).

5.4 Bliss has spoken to numerous parents whose baby or babies have been transferred long distances to find a unit that has enough staff to provide a reasonable amount of care, let alone meet BAPM and the All Wales staffing standards. According to the survey of Welsh neonatal units carried out by Bliss in 2008, between 1 April and 1 September 2007, 20 babies had to be transferred due to a lack of capacity; 27 per cent of which went outside their local area or into 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.

5.5 One mother, who had her premature son at 24 weeks, weighing just 680g, told Bliss her experience. When she started going into premature labour 9 days before her son was born, she was able to stay in her local hospital in Merthyr, but she was warned at 24 weeks she would have to be moved to a hospital with an intensive care unit.

After complications, her son was delivered by emergency caesarean section at Prince Charles and with no available cots in Wales, he was moved to Southmead, Bristol. Luckily she was able to stay in a single room in nursing accommodation at the hospital.

When he was ready to be moved back to Wales the transport team were on an emergency call and unable to collect him: by the time the team became available the cot was lost. One week later a cot became available in Newport. Later, he then suffered a setback with his eye and went to Cardiff for surgery. Eventually, 12 weeks after his birth, he was sent to Merthyr, their local hospital.

The mother said,

"Having a preterm baby is one of the hardest things anyone can ever experience and having to be away from home or facing long journeys only adds to the stress and pressure. It was a terrible experience and the lack of cots in Wales only added to the difficult situation."

5.6 Another mother described to Bliss her experience of having her premature triplets transferred to different units all around South Wales. They were born at 27 weeks, weighing between just 800g and 905g in January 2008. At 27 weeks she underwent a caesarean section at Singleton hospital, Swansea.

All babies had to be revived on delivery; the boy suffered a brain bleed and was transferred to Cardiff. After two week, one girl was moved to PCH Merthyr and the mother was allowed home the same day. The other girl was moved to Singleton as there was a shortage of specialist equipment at Merthyr.

The two girls then came home at the end of March, although one suffered a set back and spent another week in hospital. The boy suffered more problems and returned home on 8 May.

For the week that the babies were in different hospitals it felt like a lifetime to their parents. One was 25 miles to the south, one 35 miles to the east and one five minutes away from home. The mother was left torn between which baby to visit, calling every evening for an update.

5.7 In the past few years neonatal units throughout Wales have had to close to new admissions numerous times because of staff shortages. According to the Wales Audit Office report, Maternity Services, during the six-month period to 31 March 2007, 10 of the 13 Welsh Trusts reported that their neonatal units had closed to all admissions (including from within their own trust) for one or more days. And according to Bliss' survey", "between 1 April and 1 September 2007, 73 per cent of units said they had to close at some point. In a

country where care is provided in a small number of units, mostly at great distances from one another, it is unacceptable to be closing units and putting babies at serious risk.

5.8 In October 2008 the Royal Glamorgan Hospital was downgraded from a Level 3 Intensive Care Unit to a Level 2 High Dependency Unit because of a shortage of middle-grade doctors. This meant that babies born at less than 29 weeks, seriously ill babies or ventilated babies were unable to be admitted to the Royal Glamorgan neonatal unit. For three months there were six empty incubators left on the unit while mothers and babies were transferred all over the country, further away from their homes. It was only after a campaign from local parents that Edwina Hart AM announced that more funding would be put in place to recruit additional doctors.

5.9 In north Wales the service is delivered by consultants trained in paediatrics who have an interest in neonatology, meaning they are not specifically trained to carry out this role. In this respect, services in north Wales are currently falling behind most other parts of the UK. This is compounded by the severe shortage of neonatal nurses in seen throughout Wales.

5.10 There have also been problems deciding at which unit the neonatal intensive care unit in the north should be based, which has delayed the development of services. A further issue, identified by the Wales Audit Office review, is that special care cots at Aberystwyth are located on the postnatal ward and are not supported by dedicated neonatal staff. We recommend that this inquiry pays particular attention to services in north Wales.

5.11 The understaffing of neonatal services in Wales not only affects babies and their families but can have a serious effect on staff morale. One senior nurse from a very busy unit in South Wales described to Bliss the pressures they work under every day,

"Although the Welsh standards were produced over a year ago there has been no significant move towards meeting those, meaning the sickest, most vulnerable babies in the hospital still do not receive the level of care that paediatric and adult ICU [intensive care unit] patients receive. The idea of being able to give one to one nursing for our sickest patients is foremost in all the minds of my colleagues but the reality falls far short of being able to deliver that care.

Parents on the whole tend to be grateful for whatever we do but I am sure there are times when they feel their child is not being given the attention it deserves because the nurse looking after it is also looking after another sick patient. This just would not happen on adult or paediatric ITU."

5.12 Unless further investment is made available to develop the workforce in Wales, it is highly unlikely the All Wales Neonatal Standards will be met. . As Health Commission Wales' 2005 unpublished review stated: "the service has been sustained based on the goodwill of staff and their anticipation that major weaknesses in the current service will be addressed through the review". Five years on, the situation in relation to staffing has not improved.

5.13 Investing in the care of our most vulnerable babies at the start of their lives can reduce the longer term support that they may need. To this end, costs to the NHS are reduced and special care babies can go on to live healthy, happy lives, able to fulfil their potential and contribute to society.

5.14 Recommendation: We urge the Welsh Assembly Government to develop a long term workforce strategy for neonatal services in Wales to address the shortage of appropriately trained nurses and doctors and recruit, retain and train the staff needed in both the short and long term, and provide the funding and leadership to make this a reality. Staff shortages are the single biggest issue facing neonatal services in Wales, and as such Bliss recommends they should be treated as a priority by the Welsh Assembly Government.

6. Support for families

6.1 The critical shortage of neonatal nurses also has a significant impact on how the needs of families of premature or sick babies are met. Although the care of the baby should always come first, Bliss believes that too often parents are left to struggle through the pain and trauma of having a baby in need of neonatal care without any, or adequate, support. The work nurses do is always greatly appreciated by parents but due to staff shortages they often do not have the time to involve parents in the care of their baby. Nurses should be helping parents with skin-to-skin contact, breastfeeding and other family-centred care techniques. As research undertaken as part of the Parents of Premature babies Project (POPPY) has shown, involving parents in this way has been proven to have a positive effect on the health of a premature or sick baby, and can lead to the baby being discharged from hospital earlier than they otherwise would have been.

6.2 It can be extremely stressful for the parents to have their baby moved from one unit to another. Bliss recommends that a parent should always be with the baby when they are being transferred, but there is often not room in the ambulance so parents have to make their own way. Research commissioned by Bliss, published in the March 2010 edition of Infant, show's that having a baby transferred to a unit far away from the family home can have a significant emotional, practical and financial impact of the family. While some units in Wales are able to provide accommodation to parents so that they can be near their baby, access to this is patchy.

6.3 Babies in neonatal care need the nutrients that a mother's breast milk can provide even more so than other babies. One of the key recommendations in the All Wales Neonatal Standards is that breastfeeding should be actively encouraged and facilitated. However not all mothers are getting the support they need to breastfeed. One mother whose baby was on a Welsh neonatal unit commented:

"[The 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."

6.4 Travel, paying for food away from home and lost earnings through having to take time off work means the financial cost of having a baby in special care can be crippling. Bliss research released in November 2007 showed that having a sick or premature baby costs parents an extra £189 per week on average during the time their baby stays in hospital. This is on top of all the usual costs associated with having a baby. The results also show that the effect on many families' finances continues long after their baby has been discharged from hospital. Typically parents are not offered enough help to cover these costs therefore adding further anxiety to an already stressful situation. Bliss has produced a leaflet entitled "Financial help for families" which is distributed across all units and should be made available as a matter of course to all families with a baby in a neonatal unit.

6.5 Overall, having a premature or sick baby is an extremely traumatic time for a parent, yet many units still do not provide enough care for the whole family as well as the baby, either due to lack of resources or lack of understanding. Bliss believes this needs to change.

6.6 Recommendation: We recommend that all units in Wales audit their performance against the All Wales Neonatal Standards on

breastfeeding and Bliss's Baby Charter Standards to ensure they are providing care in a family-centred way.

7. Conclusion

7.1 The neonatal network and transfer service, when up and running, will make a huge difference to special care babies and their families. However, despite numerous policy initiatives over the last five years designed to address the shortcomings in neonatal care in Wales, real improvements have yet to be seen on the ground. There is still much to do before services are up to the standard that premature and sick babies need and deserve.

7.2 Bliss continues to be committed to working with the Welsh Assembly Government and NHS Wales to support the introduction of the reform outlined in this submission as soon as possible. We are calling on the Welsh Assembly Government to continue with the good work it has started for special care babies and their families, and invest the additional resources needed to fully transform neonatal services in line with the clear vision it has set out in the past 18 months.

* Hamilton K, Redshaw M, Tarnow-Mordi W, Nurse staff in relation to risk-adjusted mortality in neonatal care, Arch Dis Child Fetal Neonatal Ed 2007;92:p99-103