Cynulliad Cenedlaethol Cymru | National Assembly for Wales

Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and Education Committee

Y 1,000 diwrnod cyntaf | First 1,000 Days

FTD 44

Ymateb gan: Bliss

Response from: Bliss

1. Bliss is delighted that the Wales Assembly's Children, Young People Education Committee has recognised the importance of the first 1,000 days of a child's life for their long term outcomes and quality of life. However, it is concerning that the experiences of the 2,700 babies who are born premature or sick and in need of life-saving neonatal care every year in Wales are not specifically captured in the scope of this consultation.

2. The experience of neonatal care, which for some babies will last many months, will shape their long-term development and health outcomes. It is therefore vital that babies receive their care in a neonatal unit which is suited to their needs, and is staffed and resourced to meet national standards of safety, quality.[1]

3. <u>Nurse staffing</u>

The *All Wales Neonatal Standards* (2013) stipulate that the appropriate nurse-to-baby ratios which must be maintained to ensure safety and quality of care are: one nurse to every four babies receiving special care, one nurse to every two babies receiving high dependency care and one nurse to every baby receiving intensive care.

[1] The *All Wales Neonatal Standards* were first published by NHS Wales in 2008 and updated in 2013. They set out clear guidelines for the planning and delivery of safe, high-quality care neonatal care.

3.1. Research has shown that staffing ratios should be considered the minimum required to ensure that babies are receiving optimum care.[2] [3] It has also been established that an increase in mortality rates at level three neonatal units occurs when there is a decrease in the required one-to-one nursing for babies receiving intensive care. [4] It is therefore vital that optimum nurse-to-baby ratios are achieved and maintained.

3.2. Bliss has found that only two out of ten neonatal units in Wales had enough nurses in post to staff all of their commissioned cots in 2014/2015.[5] None of the neonatal intensive care units had enough nurses in post to care for the babies that were actually admitted, demonstrating that the busiest and most specialist neonatal units in Wales are unable to meet safe staffing levels on a day-to-day basis, potentially putting babies at risk.

3.3 To ensure babies born requiring neonatal care in Wales have the best possible chance of survival and quality of life, it is critical that these extensive nurse staffing shortages are addressed urgently. Despite recent announcements of investment to develop and expand neonatal units and obstetric care across several sites in Wales,[6] there remains a lack of investment commitments specifically for growing the neonatal nurse work force and increasing the number of child branch nurse training places. This is required to ensure that every baby born premature or sick is cared for in a neonatal unit with staffing arrangements conducive to ensuring the very best survival rates and good long-term health outcomes.

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[2] Milligan, D W, Carruthers, P, Mackley, B, Ward Platt, M P, Collingwood, Y, Wooler, L, Gibbons, J, Draper, E, Manktelow, B N (2008) 'Nursing workload in UK Tertiary Neonatal Units', *Archives of Disease in Childhood*, 93(12), pp. 1059-1064

[3] Pillay, T, Nightingale, P, Owen, S, Kirby, D, Spencer, S A (2011) 'Neonatal nursing efficacy: practical standards of nursing care provision in a newborn network', *Archives of Disease in Childhood*, 96(Suppl 1), A36

[4] Watson, S I, Arulampalam, W, Petrou, S, Marlow, N, Morgan, A S, Draper, E S, Modi, N on behalf of the Neonatal Data Analysis Unit (NDAU) and the Neonatal Economic, Staffing, and Clinical Outcomes Project (NESCOP) Group (2016) 'The effects of a one-to-one nurse-to-patient ratio on the mortality rate in neonatal intensive care: a retrospective, longitudinal, population-based study', *Archives of Disease in Childhood - Fetal and Neonatal Edition*, published online

[5] Bliss (2016) *Bliss baby report: Time for change*

[6] Welsh Government (2017) 'Over £31m to improve health services for mothers and babies' available: http://gov.wales/newsroom/health-and-social-services/2017/170113maternity/?lang=en

4. Specialist nurses

The *All Wales Neonatal Standards* and the BAPM *Service Standards* (2010) require that babies in intensive care and less stable babies receiving high dependency care should be looked after by a nurse who is Qualified in Speciality (QIS) in neonatal care. The *Toolkit for High-Quality Neonatal Services* (2009) state that a minimum of 70 per cent of the registered nursing and midwifery workforce establishment should be QIS. While this *Toolkit* standard is only directly applicable to England, it is used by the Wales Neonatal Network to assess services in Wales.

4.1. Evidence shows that maintaining a minimum 70 per cent QIS establishment improves outcomes for the smallest and sickest babies.[7] [8] Increasing the number of QIS nurses is associated with a 48 per cent decrease in mortality.[9]

4.2 Only two neonatal units in Wales were able to meet the standard of having at least 70 per cent QIS nurses.[10] No neonatal intensive care units, which provide care to the sickest and most vulnerable babies in Wales, were able to achieve this standard.

4.3 A challenge identified by all eleven neonatal units in Wales was ensuring all their nurses receive the training and development opportunities they need; a significant barrier to increasing the levels of QIS nurse across Wales.[11] Most commonly, units struggled to release nurses from their frontline duties for training due to an inability to backfill these posts, highlighting how neonatal nurse shortages contribute to other difficulties, and prevent a spectrum of evidence-based standards from being met.

4.4 Bliss urges the Government and Health Boards to put medium to long-term plans in place which address the nursing skills shortages and training issues identified in the *Bliss baby report: Time for change*, so every critically ill baby born in Wales is treated by nurses with proven competencies to

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[7] British Association of Perinatal Medicine (2010) *Service Standards For Hospitals Providing Neonatal Care*
[8] Hamilton, K E, Redshaw, M E, Tarnow-Mordi, W (2007), 'Nurse staffing in relation to risk adjusted mortality in neonatal care', *Archives of Diseases in Childhood – Fetal and Neonatal Edition*, 92(2), F99-F103
[9] Hamilton et al. (2007)
[10] Bliss (2016) *Bliss baby report*
[11] Bliss (2016) *Bliss baby report*

provide specialist care. This will improve long-term health outcomes as babies develop through their first 1,000 days and into their childhood, and could contribute to lowering the infant mortality rate over time.

5. Medical Staffing

BAPM *Service Standards* recommend that all neonatal units should have a minimum of eight tier one (junior) staff, eight tier two (middle grade) staff and seven tier three (expert) staff members on medical staffing rotas. All medical staff working in neonatal intensive care units should have their clinical time devoted to neonatal care; with no crossover with paediatrics. There are far fewer medical staff than nurses in neonatal units, so even one or two gaps on a medical rota can significantly impact on babies' care and how effectively the unit runs.

5.1 Over half of all neonatal units, did not have enough medical staff to meet minimum standard for safe, high-quality care.[12] Of particular concern is that six units did not have enough tier three (expert) staff members in post.

5.2 A lack of funding is one of several large contributory factor for these shortfalls. Even if all medical vacancies were filled at the six units unable to meet minimum standards on medical staffing levels, four units would still not have had enough medical staff in place during 2014/2015.[13] Persistent recruitment challenges and the impact of visa restrictions on international workers are also contributing to this shortfall.

5.3 Half of neonatal units in Wales do not have the expert and middle grade medical staff they need to be able to minimum standards for quality and safety. Shortages across multiple levels of seniority could make it especially difficult for units to cope and provide a safe level of care. A significant investment commitment is required alongside collaborative workforce planning to ensure all units are appropriately staffed, and to guarantee babies born premature or sick have the best possible outcomes.

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[12] British Association of Perinatal Medicine (2010) *Service Standards For Hospitals Providing Neonatal Care*
[13] Bliss (2016) *Bliss baby report*

6. Allied health professionals

The *All Wales Neonatal Standards* and the BAPM *Service Standards* outline the range of allied health professionals who are needed to support babies, including physiotherapists, occupational therapists and speech and language therapists. They have an important role in promoting babies' neurodevelopment, reducing pain and supporting feeding.

6.1 Bliss findings have shown that access to these professionals is patchy.[14] One neonatal intensive care unit had no access to an occupational therapist, speech and language therapist or neonatal pharmacist, even via referral to another service. If babies do not receive support from the full range of neonatal professionals, this can have an impact on the safety of their care and their long-term health and development. For example, poor nutrition or pain management may affect babies' neurodevelopment as they get older.[15] [16] [17]

6.2 Investing in the right treatment and therapies for babies can affect how much support they need from the health and social care system as they grow up, so it is important for individual babies, families and the public finances that NHS Wales is sufficiently funded to provide this professionals.

6.3 These persistent and wide-spread workforce challenges need to be addressed urgently. Staffing levels which do not meet evidence based neonatal standards will affect the first 1,000 days for babies born needing life-saving neonatal care, and their longer-term outcomes.

7. Reducing infant mortality

The *All Wales Perinatal Survey* (AWPS), has collected neonatal mortality and stillbirth data annually since 1993. While it is excellent that the overall neonatal mortality and stillbirth rate has declined over this period, it is of

[14] Bliss (2016) *Bliss baby report*

[15] Eckstein Grunau, R (2013) 'Neonatal Pain in Very Preterm Infants: Long-Term Effects on Brain, Neurodevelopment and Pain Reactivity', *Rambam Maimonides Medical Journal*, 4(4), published online

[16] Ranger, M and Grunau, R E (2014) 'Early repetitive pain in preterm infants in relation to the developing brain', *Pain Management*, 4(1), pp. 57–67

[17] Prado, E and Dewey, K (2012) 'Insight: Nutrition and brain development in early life', *Alive & Thrive Technical Brief*, (4)

great concern that the neonatal mortality rates remain persistently higher in the two most deprived quintiles of social deprivation.[18]

7.1 In 2015 there were 83 neonatal deaths across Wales and 138 stillbirths.[19] It is alarming that neonatal and infant mortality rates are almost 50 per cent higher in the most deprived areas of Wales compared to the least deprived.[20]

7.2 The researchers also note that preterm birth is a major cause of neonatal mortality. There is little socio-economic variation in mortality following preterm birth, indicating good equity in health care provision but preterm birth rate is higher in deprived areas, which drives the socio-economic inequalities which are seen in neonatal mortality rates.

7.3 The *State of Child Health* report from the Royal College of Paediatrics and Child Health reflects the impact social deprivation has on health and mortality outcomes. Babies born in in poverty are 50 per cent more likely to suffer stillbirth or neonatal death, and more than twice as likely to die in infancy as those from the most affluent families.[21] As well as monitoring trends, urgent investment and planning is needed to implement strategies to reduce the mortality rate and close the inequality gap in Wales.

7.4 Bliss recommends that the AWPS own recommendation to implement a robust system to assess stillbirth and neonatal death throughout Wales is put in place.[22] We would recommend that units engage with the standardised perinatal mortality tool once available.

8. <u>Reducing the adverse impact of psychosocial issues: mental health</u>
It is excellent that the Welsh Government's *Together for Mental Health Delivery Plan 2016-2019* highlights the need for improved access to perinatal mental health services. Key aims for every health board to have a perinatal health service and ensuring women who are identified as having

[18] All Wales Perinatal Survey (2015) *Annual Report 2015*, available online: http://awpsonline.uk/reports/awps2015/
[19] All Wales Perinatal Survey (2015) *Annual Report 2015*
[20] Welsh Government (2016), *Chief Medical Officer for Wales Annual Report 2015-2016*
[21] Royal College of Paediatrics and Child Health (2017) *State of Child Health*
[22] All Wales Perinatal Survey (2015) *Annual Report 2015*

serious pre-existing mental health conditions are referred to specialist services are particularly welcome.[23]

8.1 However, it is concerning that there is no reference of support specifically for parents whose baby is admitted to neonatal care, nor are they considered a high-risk group for adverse mental health outcomes. Parents whose baby is admitted to neonatal care are more likely to suffer from mental health problems, with up to 40 per cent of mothers of premature babies affected by postnatal depression.[24] The *All Wales Neonatal Standards* state that families should have access to psychiatric support and psychological advice from clinical psychologists specialising in neonatal care. The BAPM *Service Standards* also require that neonatal intensive care units provide access for parents to a trained counsellor from the time their baby is admitted.

8.2 Despite this, Bliss' research shows that only five out of 11 neonatal units in Wales were able to offer parents access to psychological support of any kind. No neonatal intensive care units had a dedicated trained mental health work available to parents without delay.[25]

8.3 Bliss recommends that Health Boards, with advice from the Wales Neonatal Network, look at how to ensure there are enough trained mental health workers available across neonatal care. Optimum staffing is vital to ensure that parents have dedicated support, and is essential for outcomes for babies throughout their first 1,000 days.

9. Improving child health outcomes: two year check-up

The 'two-year check', performed by a neonatal consultant, is essential for monitoring the developmental progress of babies born premature post-discharge, and helps to highlight developmental delay and offer an opportunity for early intervention.

[23] Welsh Government (2016) *Together for Mental Health: Delivery Plan: 2016-19*

[24] Vigod, S N, Villegas, L, Dennis, C L, Ross, L E (2010) 'Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review', *BJOG*, 117(5), pp. 540-50

[25] Bliss (2016) *Bliss baby report*

9.1 It is deeply worrying that the latest data from the Neonatal Audit Programme shows that 67 percent of preterm babies in Wales have no follow up health data recorded at all.[26]

9.2 Bliss recommends a review to assess why so many children are currently failing to have their two-year check, and a robust system put in place to increase participation in this important aspect of follow-up care.

9.3 Good developmental follow-up is important to ensure that babies have the best chance of positive long-term outcomes. Early interventions and referral to necessary therapies can improve their developmental outcomes – but only if issues can be identified early.

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[26] National Neonatal Audit Programme (2016) *2016 Annual Report on 2015 data*