Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Flaenoriaethau'r Chweched Senedd

This response was submitted to the Health and Social Care Committee consultation on Sixth Senedd Priorities

HSC PSS 96

Ymateb gan: | Response from: Bliss

Question 1: Initial priorities identified by the Committee

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

Q1. Which of the issues listed above do you think should be a priority, and why?

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

Around 3000 babies are born premature or sick across Wales every year and receive care in a specialist neonatal unit shortly after they are born. Many of these babies will remain in hospital for a few days, while others will receive life-saving care for weeks or months before they are ready to go home. Very sadly, some babies will never go home at all.

The recent review into maternity services at Cwm Taf Health Board[1] had shone a light on the need to renew focus on ensuring high-quality care nationally, for babies born premature or sick, with a family centred care approach.

Priority areas for improvement in Wales' neonatal services align well with the initial priorities identified by the committee for work during the Sixth Senedd, and we would encourage the committee to explore the issues relating to staffing and parental mental health outlined below over the course of the 6th Senedd, as well as considering a focus on neonatal mortality and the impact of COVID-19 on neonatal services.

<u>The health and social care workforce, including organisational culture and staff wellbeing</u>

1. **<u>Neonatal nursing</u>**

[1] https://gov.wales/sites/default/files/publications/2019-04/review-of-maternity-services-at-cwm-taf-health-board_0.pdf

Neonatal services in Wales are commissioned according to the Wales Neonatal Standards 3rd edition[2] and British Association of Perinatal Medicine (BAPM) standards[3]. The Standards detail that the minimum nurse-to-baby ratios which will enable safe and effective care to babies requiring neonatal care (excluding shift coordinators and other supernumerary staff):

- **Special care: there should be a minimum staff-to-baby ratio of 1:4 at all times.**
- **High dependency care: there should be a minimum staff-to-baby ratio of 1:2 at all times.**
- **Intensive care: there should be a minimum staff-to-baby ratio of 1:1 at all times.**

The All Wales Neonatal Standards and the BAPM Service Standards require that babies in intensive care and less stable babies in high dependency care should be looked after by a nurse who is Qualified in Speciality in neonatal care. More stable babies in high dependency and those in special care should be looked after by nurses who are under the direct supervision and responsibility of a specialist neonatal nurse.

The Toolkit for High-Quality Neonatal Services, published in 2009, states that a minimum of 70 per cent of the registered nursing and midwifery workforce establishment[4] should be Qualified in Speciality.[5] While this standard is only directly applicable in England, it is used by the Wales Neonatal Network to assess services in Wales.

According to National Neonatal Audit Programme (NNAP)[6] data, in Wales 81 per cent of neonatal unit shifts were numerically staffed to meet guidelines in 2019.

While Wales performs well compared to other neonatal networks in Britain when assessing compliance with nurse staff on shifts, it is imperative not to become complacent. A fifth of shifts not meeting compliance is a concern, particularly as nurse staffing levels directly correlate with mortality rates, with research showing that infants cared for in a setting with higher nurse-to-baby ratios have an improved adjusted risk for survival. The most recent research published in 2016 by Watson et al.[7] established that an increase in mortality rates at NICUs occurred when there was a decrease in the required one-to-one nursing for babies receiving the most intensive level of care. It is therefore vital that sufficient numbers of nurses are available on a unit, otherwise babies could be put at risk.

[2] https://collaborative.nhs.wales/files/maternity-and-neonatal-network/allwalesneonatalstandardsthirdedition-pdf/

[3] https://hubble-live-assets.s3.amazonaws.com/bapm/file_asset/file/75/Service_Standards_for_Hospitals_Final_Aug2010.pdf

[4] The workforce establishment is the total number of posts, including vacancies

[5] Department of Health (2009) Toolkit for High Quality Neonatal Services, p. 40

[6] https://nnap.rcpch.ac.uk/

[7] Watson, et al 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

As well as ensuring the overall nurse-to-baby ratios are sufficient, it is essential that enough nurses with the right skills are available on a unit. In a study of 54 neonatal intensive care units in the UK that having more nurses Qualified in Speciality (QIS) than the standards recommend, reduced the risk of mortality by 48 per cent[8].

Only 38 per cent of units in Wales had enough nurses who had completed Qualified in Speciality (QIS) training working on them. Urgent action is required to ensure there is an appropriate plan and resources in place to ensure nurse staff have access to QIS training.

2. **Medical staffing**

The All Wales Standards, BAPM Optimal Arrangements for NICU (BAPM, updated 2021), and Optimal Arrangements for Local Neonatal Units and Special Care Baby Units (BAPM, 2018) set out the required medical staffing across each tier.

Recent data from the Royal College of Paediatrics and Child Health (RCPCH) and Getting It Right First Time (GIRFT)[9] found 13 per cent of neonatal units in Wales had gaps in medical staffing with 10 per cent covered by locums.

Neonatal units need to have the right number and mix of medical staff in order to manage babies' care safely and effectively. There are far fewer medical staff working on neonatal units compared to nurses, so even one or two gaps on a medical rota can have a big impact on babies' care, and how effectively the unit is operating.

3. **Allied Health Professionals (AHPs)**

For babies born requiring neonatal care to have the best chance of survival and quality of life, they need input from of a whole range of professionals. While neonatal nurses and doctors provide the majority of their care, a multi-disciplinary team including (but not limited to) occupational therapists, speech and language therapists, physiotherapists and pharmacists come together to provide a comprehensive assessment and care plan individualised to each baby's needs.

If babies are unable to receive support from the full range of professionals when they need it, it can have a lasting effect on their long-term development and health. For example, poor nutrition or pain management can have a significant impact on a baby's neurodevelopment as they get older. It is essential that all babies, and families, have access to the full complement of professionals, yet this is not the case for a significant number of neonatal admissions who would benefit from them.

The All Wales Neonatal Standards and the BAPM Service Standards outline the range of professionals with specialist knowledge and skills who babies need to be supported by. These include physiotherapists, occupational therapists and neonatal speech and language therapists, all of whom play a very important role in supporting families, promoting babies' neurodevelopment, reducing pain, improving communication and supporting

[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] https://www.rcpch.ac.uk/resources/snapshot-neonatal-services-workforce-uk

feeding. All units should have a designated nurse with responsibility for breastfeeding, and babies should have access to a dietitian and a pharmacist who should both have specialist knowledge of neonatal care.

Bliss' 2016 report Bliss Baby Report 2016: time for change[10] showed that there is inconsistent access to these professionals at neonatal units across Wales. A survey of neonatal units in Wales found that five out of 11 units in Wales, including two out of three neonatal intensive care units, had no access to an occupational therapist, even via referral to another service. Three units had no access to a speech and language therapist and three had no access to a specialist radiographer. Worryingly, one neonatal intensive care unit had no access to an occupational therapist, speech and language therapist or a neonatal pharmacist, even via referral to another service.

Even fewer units had professionals with dedicated time in their work plan to spend with babies, families and staff on the unit each week. There are important advantages to working regularly on a neonatal unit, as professionals can integrate into the neonatal team, influence the way that the team works, and get to know families.

Access to mental health services

Having a baby who is admitted to neonatal care is very stressful and traumatic for parents, and they often need emotional support to help them cope. Parents of babies receiving neonatal care are more likely to experience mental health problems as a result of their experience.

Research shows that mothers of babies who are admitted to neonatal care are up to 40 per cent more likely to suffer from post-natal depression and other mental health conditions compared to the general population[11]. Parents with existing mental health problems prior to the birth of their baby may be exacerbated by the trauma of birth and the experience of having a sick baby. Bliss' research has also shown that parents need emotional support while their baby is receiving care, a 2018 survey found that 80 per cent of parents said their mental health was negatively impacted as a result of their experience[12].

As such, it is important that families receive support throughout their journey, including post-discharge, from professionals who have experience of working with families affected by neonatal care, and that services are organised so families who may face regular ongoing hospital appointments and re-admissions are able to access the support they need.

[10] https://s3.eu-west-2.amazonaws.com/files.bliss.org.uk/images/Bliss-baby-report-2016-Time-for-change-Wales.pdf

[11] 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

[12] https://www.bliss.org.uk/parents/support/impact-mental-health-premature-sick-baby/is-it-common-for-parents-to-struggle-with-mental-health

The All Wales Neonatal Standards state that families should have access to support services which include a social worker, bereavement counsellor, psychiatric support and psychological advice by trained clinical psychologists specialising in neonatal care. The BAPM Service Standards are also clear that at neonatal intensive care units parents should have access to a trained counsellor without delay from the time their baby is admitted, and there should be ongoing support during the parents' time on the neonatal unit.

However, in 2016[13] Bliss found that Neonatal Units across the country were unable to provide this essential support for parents.

- **Only five out of 11 neonatal units in Wales were able to offer parents access to psychological support of any kind, either on the unit or via referral to another service.**
- **None of the three neonatal intensive care units had a dedicated trained mental health worker available to parents without delay, as required by the BAPM Service Standards.**
- **Parents at two neonatal intensive care units were not able to access this support at all, even via referral to another service outside of the neonatal unit.**

While there has been some increase in provision since 2016, this is still extremely patchy and may be unsustainable in some places (dependent on charitable funding). This means that parents with the most critically ill babies in Wales, and the staff members who look after these babies, may be left without the help and support they need.

In Bliss' 2018[14] survey of parents, we found that 62 per cent said they had no formal psychological support while their baby was in neonatal care, and 45 per cent said they had no formal psychological support once they had left the unit.

This lack of support from dedicated professionals is exacerbated by staffing shortages across neonatal care. This means that, despite the huge dedication and hard work of the doctors, nurses and other professionals working in neonatal care, parents who experience the trauma of having a newborn baby admitted to neonatal care are often left to try to cope alone.

The parents of babies born premature or sick must have access to mental health and wellbeing support at the appropriate level at all points in their journey.

There is a key opportunity for the Health and Social Care Committee to shine a spotlight on psychological support services in neonatal settings. Following Bliss' evidence to the Children, Young People and Education Committee in their enquiry into perinatal mental health in Wales15 in 2017, the committee recommended that the Welsh Government set out how it expects the lack of psychological support for neonatal and bereaved parents to

[13] https://s3.eu-west-2.amazonaws.com/files.bliss.org.uk/images/Bliss-baby-report-2016-Time-for-change-Wales.pdf

[14] **https://www.bliss.org.uk/parents/support/impact-mental-health-premature-sick-baby/is-it-common-for-parents-to-struggle-with-mental-health**

[15] https://senedd.wales/laid%20documents/cr-ld11234/cr-ld11234-e.pdf

be addressed. Although the Government accepted this recommendation, and a standard is included in the All Wales Neonatal Standards. However, no significant progress has been made to provide mental health support to parents with a baby born premature or sick in Wales.

Question 2: Key priorities for the Sixth Senedd

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

a) **health services;**
b) **social care and carers;**
c) **COVID recovery?**

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

a) Health services

b) Social care and carers

c) COVID recovery

<u>COVID-19 restrictions on neonatal units</u>

Neonatal units have been highly impacted by the COVID-19 pandemic over the last year and a half. Despite the growing body of evidence detailing the adverse outcomes of separating parents from their babies during the pandemic, and national commitments to ensure neonatal care is provided in Family Centred Care environments, the restrictions put in place to ensure the safety of babies, staff and parents at the beginning of the pandemic remain in place.

Bliss' research shows the devastating impact that access restrictions to neonatal units can have on parents and their babies. In a survey of 510 parents, respondents told us that they were not able to be with their baby when they needed to be. Parents told Bliss that being unable to parent together or only able to attend the unit for a limited period of time was extremely difficult as it left them without the support of their partner at one of the most difficult times in their lives. It meant parents missed out on opportunities to be involved in their baby's care and decision making, with the parent on the unit being left to pass on updates, including life-changing news. This has had a detrimental impact on many parents:

- **Nearly three-quarters of parents (72%) who said they could not parent together also said their mental health was negatively affected.**
- **Parents were 70% more likely to say they found it difficult to bond with their baby if the neonatal unit where their baby was being cared for had put time limits in place, as part of COVID-19 parent access restrictions.**

The Neonatal Network has also undertaken an assessment and found restrictions on neonatal units during the COVID-19 pandemic have had a significant impact on neonatal families in Wales.

Unfortunately, while the wider COVID-19 restrictions have been eased in much of the rest of society, neonatal units across Wales are still routinely restricting parents' access to their sick babies. This is an urgent issue and we would suggest this is considered by the committee, both a as an area for immediate action but also a area that requires the attention of the committee in any work looking back at the government's COVID-19 response.

Key stakeholders to include on this issue will be parents – to help the committee understand the severity of the COVID-19 restrictions on parents and their babies while they were receiving neonatal care and the ongoing ramifications of this.

Question 3: Any other issues

Q3. Are there any other issues you wish to draw to the Committee's attention?

Reducing neonatal mortality

Bliss recommends that the Health and Social Care Committee undertake work to drive forward improvements to reduce maternal deaths, stillbirths, neonatal deaths and premature births.

Unfortunately, the neonatal mortality rate (death within the first 28 days of life) in Wales has not significantly reduced since 2013 and was 3.3 per 1,000 total births in 2019[16]. The stillbirth rate in Wales increased in 2019 – from 3.8 to 4.6 per 1,000 births[17] - and there are still far too many unexplained infant deaths in Wales – at a rate of 0.30 per 1,000 live births in England and Wales[18].

As a member of the Pregnancy and Baby Charities Network (PBCN), Bliss supports the need for national targets to reduce maternal deaths, stillbirths and neonatal deaths and premature births. This requires political oversight and championing at the highest level.

While the Welsh Government are committed to reducing the rate of babies dying, they have previously resisted calls for a target, saying the population is too small. However, with similar cohorts, it is still possible to track trends over time, which is already happening. Comparisons are in the public domain at Health Board level in Wales, and Office for National Statistics data are broken down nationally. These clearly show the lack of a target and concerted efforts to reduce the rate of babies dying in Wales is resulting in poorer outcomes for babies and families.

The Welsh Government's Maternity Care in Wales -A Five Year Vision for the Future 2019 - 2024(the Vision) states *"Quality assurance of maternity service delivery across Wales will be led by Welsh Government performance board review in conjunction with Healthcare Inspectorate Wales (HIW) assessment. This will be informed by the All Wales Maternity Performance outcome indicators."*

The All Wales Maternity Performance Indicator dataset must include a target to reduce stillbirth and neonatal death rates, which Is reported against annually.

In England and Scotland, high profile targets to reduce neonatal death, and other forms of pregnancy and baby loss, have driven meaningful activity to reduce the rate of baby deaths. Political accountability is necessary to stop Wales continuing to fall behind the rest of the UK.

Inequalities

It is also clear that work is needed in Wales to ensure that any improvements in stillbirth and neonatal mortality are equitable. Compared to White babies, neonatal mortality rates for Black/Black British babies and for Asian/Asian British babies are 1.7 times higher/ The

[16] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2019#main-points

[17] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2019#main-points

[18] https://www.lullabytrust.org.uk/professionals/statistics-on-sids/

difference in neonatal death rates between Black/Asian babies and White babies appears to be increasing. For Babies from the most deprived families, neonatal death rates are 1.6 times higher than the least deprived.

We recommend that the committee considers the inequality in outcomes seen based on ethnicity, postcode and family income.