

## Summary

1. Bliss welcomes the Committee's focus on perinatal mental health and its interest in how services are complying with national standards. We would like to draw particular attention to the mental health needs of mothers of premature or sick babies, which can be significantly different and more prevalent than those of the wider maternity population. Bliss' research has found that, while national standards exist for mental health services for mothers of babies in neonatal care, psychological support on neonatal units in Wales is woefully insufficient and requires urgent attention.

## Neonatal services in Wales

2. Every year, over 2,700 babies in Wales are admitted to neonatal services for lifesaving care. That means that one in 12 of all babies born in Wales is admitted to neonatal care because they are premature or sick. The care that these babies receive in the first few hours, days and weeks of their life is absolutely crucial so that they have the best possible chance of survival and going on to have a good quality of life.
3. Premature and sick babies are currently cared for in 11 neonatal units across Wales. The service provided across these units is co-ordinated by the Wales Neonatal Network which advises Health Boards and works with units and neonatal transport services to ensure that babies receive the care they need, as close to home as possible.
4. In 2010, the Health, Wellbeing and Local Government Committee conducted an Inquiry into Neonatal Care, and progress was reviewed by the Children and Young People Committee in 2012. These cross-party reports expressed serious concern about medical and nurse staffing levels in neonatal care and set out recommendations to address the challenges facing the service in Wales.
5. In 2016 Bliss published the Wales Bliss baby report: time for change which found that neonatal services still do not have the staff and resources that

they need to be able to meet the *All Wales Neonatal Standards*, putting babies' safety and long-term health at risk. Specifically in relation to mental health, the report showed that **parents have no access to any psychological support** at over half of units.

### **Mental health for parents of premature or sick babies**

6. When a baby is born premature or sick, it is an extremely stressful and anxious time for parents. In most instances, parents will not know in advance that their child will require specialist care after birth and this shock can compound their feelings of stress and loss. It is therefore vital that there is adequate access to psychological support from admission to the neonatal unit, as well as after a baby has been discharged home.
7. Evidence shows that mothers of babies 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 of new mothers.<sup>i</sup> A 2015 study recommends that the emotional needs of parents in the neonatal unit are of equal importance to the development of their babies and must have frequent input from experienced neonatal mental health professionals to support them throughout their stay.<sup>ii</sup>
8. Neonatal units are often located far from family homes, meaning parents often find themselves unable to be with their baby for as long as they would like due to long and expensive travel to the neonatal unit. This can also be an incredibly expensive time as parents need to pay for additional travel, food, childcare for older children and accommodation to be near their baby on top of all the normal baby costs. Parents in Wales told us that they spent an extra £260 for every week their baby was in neonatal care.<sup>iii</sup>
9. This creates real barriers to parents being with, and caring for their baby. Some parents will not be able to visit their baby every day at all. Of the parents who responded to Bliss' survey 54 per cent reported that cost of travel affected their ability to visit their baby at least some of the time, and 64 per cent felt their ability to visit their baby was affected by the distance they had to travel at least some of the time. This has a real impact. Parents reported that not being able to be with their baby as much as they wanted to affected how well they bonded together.<sup>iv</sup> This seemed to be a particular

difficulty for fathers who usually have to return to their normal working hours long before their baby is discharged.

“I was very isolated because I had to travel to Liverpool to be with my baby. This contributed massively to my Postnatal Depression, which affected bonding” (Mother of a baby born at 25 weeks)

10. The additional financial pressure causes additional stress and worry to families, and this in itself can have an impact on parent’s mental health. One in two parents reported that their mental health had worsened as a result of the financial burden, and nearly a fifth said that their mental health was ‘significantly worse’.<sup>v</sup>

#### **Current standards for perinatal mental health within neonatal services in Wales**

11. The Welsh Government’s *Together for Mental Health Delivery Plan 2016–2019* highlighted the need for improved access to perinatal mental health services. We particularly welcomed its key aims for every health board to have a perinatal health service, and ensuring women who are identified as having serious pre-existing mental health conditions are referred to specialist services.<sup>vi</sup>
12. 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.
13. 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. The *Bliss Baby Charter* states that parents and families should have access to psychosocial support.
14. Despite this, Bliss’ research shows that:
  - Only 5 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.

- 0 out of 3 NICUs had a dedicated MH work available to parents without delay.
- 2 out of 3 NICUS were unable to offer parents any trained MH support at all, even via referral.
- Parents of the most critically ill babies are often left without any emotional support or psychological help.<sup>vii</sup>

“No psychological support was offered. The nurses provided me with support on emotional days but it was quite a lonely experience, day after day of sitting next to an incubator for hours on end.”  
(Mother of baby born at 32 weeks)

15. **Recommendation:** National policy on perinatal mental health must acknowledge the significant impact of having a premature or sick baby on maternal mental health, and identify this group as being at high risk of adverse outcomes.
16. **Recommendation:** Health Boards, with advice from the Wales Neonatal Network, should 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.

### Space for support

17. Neonatal units should have sufficient facilities to enable psychological support to be provided appropriately. When a baby dies or their condition is deteriorating it is important that parents have space to not only come to terms with the news and to express their initial sadness and grief in a safe environment, they also need a room so they can spend time with their baby after their death to say goodbye and to make their last memories.
18. In England we found that, while some units have dedicated bereavement facilities, many units do not and rely on normal accommodation or quiet rooms. Not only can availability be an issue, which may impact on a family’s privacy, but the time they want to spend with their precious baby may be cut short.
19. Sufficient accommodation is an essential component of good bereavement facilities, especially in the absence of a dedicated

bereavement suite. The *All Wales Neonatal Standards* state that neonatal units should provide one room per intensive care cot for parents which should be free of charge, have bathroom facilities, and be within a ten to 15 minute walk of the unit. However, our research has shown that none of the three neonatal intensive care units had enough parent accommodation to meet the All Wales Neonatal Standards requirement for one room per intensive care cot. Of the three local neonatal units in Wales that had intensive care cots in regular use, only two had sufficient parent accommodation to meet these standards.

“There definitely needs to be a counselling service for parents. Having a premature baby is traumatic, especially when they have health issues or when there is a death. The nurses on the unit were fantastic and talked to me a lot about what was happening. They supported me through my daughter’s palliative care and helped with funeral arrangements. However, having spoken to other parents we all agree that we needed some counselling.” (Mother of twins born at 24 weeks)

### Support out of area

20. Families of the sickest babies may receive care at a neonatal unit within a different Health Board, which can lead to difficulties in accessing ongoing psychological support when they move to a hospital closer to home. It’s vital that continuity of psychological support is considered in the planning of services to avoid parents falling through the gaps. While work is being undertaken to put in place community perinatal mental health services in each Health Board region, it is Bliss’ understanding that the specific needs of families experiencing neonatal care are not yet a part of this process.
21. **Recommendation:** Mental health provision on neonatal units must be joined up across Health Board areas, and with local community services, to ensure a simple pathway for families who receive care on more than one neonatal unit and those who need continued support once their baby has been discharged.
22. **Recommendation:** Service planning and referral pathways should also be sensitive to the needs of families who may be with their baby at a neonatal unit far from home, and who may not be in a position to travel to services located in a separate location for weeks or months.

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<sup>i</sup> 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

<sup>ii</sup> Hynan, M.T., Steinberg, Z., Baker, L., Cicco, R., Geller, P.A., Lassen, S., Milford, C., Mounts, K.O., Patterson, C., Saxton, S., Serge, L., Stuebe, A.,(2015) 'Recommendations for mental health professionals in the NICU,' *Journal of Perinatology*, 35 S14-S18

<sup>iii</sup> Bliss (2014), *It's not a game: the very real costs of having a premature or sick baby in Wales*

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<sup>vi</sup> Welsh Government (2016) Together for Mental Health: Delivery Plan: 2016-19

<sup>vii</sup> Bliss (2016) Bliss baby report