Neonatal Leads for Psychological Practice in England - Written evidence (PRT0052)

Introduction

The NeoLeaP group represents the psychological leadership for Neonatal Care across England. We are a group of Consultant Clinical Psychologists leading on psychological provision for neonatal services across the 10 Neonatal Operational Delivery Networks in England and we are pleased to contribute to this Committee, which is very timely at such a psychologically challenging point for all those within neonatal care.

We believe that integrated psychological support for infants, families, healthcare professionals and provider organisations would have wide ranging benefits. Ultimately, allocating resources in a preventative and holistic way for those known to be at high risk of poorer outcomes is both effective and efficient.

We have attempted to provide a brief summary of some of the key issues at play, in response to the particular highlighted areas of consideration. We have provided references where possible within the timeframe and are happy to share further references and resources as needed.

Variation in care and health inequalities

There are a range of factors that contribute to health inequalities in the neonatal population. Families who are disadvantaged socio-economically and those from minoritised ethnic groups are at increased risk of

- preterm birth
- the kind of congenital conditions that result in term admission to neonatal care
- death, for both infants and mothers

For example, babies in England and Wales in the Black ethnic group have the highest proportion of preterm births (8.7% in 2021[i]) which in the context of identified racial injustice in the perinatal system[ii] further increases the risk of trauma. Those for whom English isn't their first language, who identify as LGBTQIA+, who are neurodivergent, have learning disabilities or pre existing complex mental health needs are all at greater risk of being traumatised both the experience of birth and that of neonatal care and these families require individualised, psychologically informed care planning to minimise the risk of iatrogenic harm to individual and family outcomes in the longer term.

Many of these risk factors are, independently, also risk factors for mental ill-health, and are often factors that are linked with lower levels of access to existing psychological support services, further amplifying health inequalities.

What might help:

- Integrating specialist psychological support services into neonatal care reduces the barriers to access
- Properly funded, supported and governed models of peer support allow parents to feel seen, heard and understood[iii]
- Consideration of the psychological needs of the neonatal workforce, who might find it more challenging to practice in inclusive and responsive ways when their own psychological needs are not supported and they don't have the tools to understand what babies, families, themselves and each other are experiencing[iv,v]

Trauma informed care (TIC) is an evidence-based model to reduce health inequalities. While the principles of TIC are easy to cite, developing trauma informed services involves more than one-off training events. At the heart of this approach are systems that create a sense of safeness, space to think and reflect together, promote mentalisation (seeing others' perspectives) and allow for this approach to be embedded as part of the

culture. This requires an investment in training and facilitation but also in giving all staff adequately funded time to attend to the relational and psychological aspects of their work.

Prevention of preterm birth (and the associated psychological trauma)

The NICE guidelines for preterm birth give clear direction as to the importance of the conversation that happens with families antenatally when they are at increased risk of preterm birth. While this is a medically driven conversation, there are a large number of psychological components and the conversation requires considerable skill to mitigate trauma and help parents collaborate in developing and fully understand a plan that feels right for them and their baby. There is evidence of the need to consider a wide range of psychosocial factors in decision making, particularly at the margins of viability[vi]. Input from psychological professionals and a system of psychologically informed care can support:

- Ongoing training for staff in how to consider the holistic needs of babies, parents and families
- Spaces to think, learn and acknowledge the distress inherent in these conversations for both parents and staff
- Direct support for families and the MDT to make this process feel as safe and supported as possible and mitigate trauma.

Neonatal and longer-term care and support

Impact on psychological outcomes

While the survival rates of preterm infants have improved significantly in recent years, the neurodevelopmental outcomes for infants have not kept pace[vii]. The future direction of hospital care is likely to include an increased proportion of infants with complex needs, many of whom will

have been born preterm. With medical complexity comes a complexity of psychological impact:

- how infants grow, develop and make sense of their own needs and relationships as they move through childhood, adolescence and adulthood
- how parents, siblings and the wider family adjust to the needs of their child, including the impact on their own mental health and wellbeing
- and how healthcare professionals navigate their own experiences of caring for these infants and families, including the conflict and significant distress that often arises in these relationships where outcomes are so precarious.

There is now strong evidence that experiencing a preterm birth and a stay on the neonatal ward, can have significant detrimental impact on the mental health and wellbeing of new parents[viii]. Research indicates that up to 40% of mothers experience symptoms of Post Traumatic Stress Disorder 6 months after birth, with 1 in 4 mothers still experiencing these symptoms for up to 18 months[ix]. Reported parental stress for infants increases with infants with lower gestational ages and lower birth weights[x]. Rogers et al. (2013)[xi] found that at discharge from the NICU, 20% of mothers had clinically significant levels of depression, with 43% having moderate to severe anxiety.

The impact on parental mental health has long been recognised to have a subsequent impact on the quality of attachment relationships between parents and their infants[xii]. Babies' experiences of embodied medical trauma following birth or a prolonged hospital admission and their enforced separation from parents can also have huge physical, developmental and mental health consequences throughout their life[xiii]. Recognition is building that neonatal care can be seen as a key traumatic

Adverse Childhood Experience (ACE) that predisposes an infant to longer term adverse outcomes[xiv].

In addition to individual impacts, the stress and distress of preterm birth can also pervade the wider family system, impacting on the experiences of siblings, couple and wider family relationships and the ways in which families develop and relate to each other and their preterm baby in the longer term[xv,xvi].

Neonatal MDT professionals (nurses, doctors, AHPs, auxillary staff) act as containers for the distress of babies and families in their care, as well as carrying their own distress relating to the work. It is very demanding for staff to work in this environment without either projecting their distress back towards families (resulting in poorer care outcomes and potential conflict / litigation) or turning it inwards and increasing burnout and sickness. The evidence base for staff in critical care is well established[xvii], with specific evidence showing that 40% staff in paediatric settings are experiencing one or more of burnout, moral injury or post traumatic stress symptoms[xviii].

What is needed?

The BAPM-endorsed Psychological Staffing Standards[xix] that are part of the new NHSE Neonatal Service Specification[xx] highlight the need for a model of psychological support across multiple tiers:

- Offering universal, targeted and specialist level interventions, embedded in and working
- That mitigate the impact of neonatal care on babies, parents, families and staff

Support for babies, parents and families

The Ockenden report prioritised Psychological support to families and conclude "The availability of dedicated expert support has meant families have not had to manage…alone, and have been empowered to have the opportunity to reflect on and understand what they have been through' and '…in the future, this model of family support should be used to inform good practice' (Ockenden, 2022 p.28)[xxi].

Standards from the USA recommend the provision of universal screening of psychological needs for families in the neonatal unit to promote the early recognition and preventative approach to distress that might result in longer term psychological harm. Although not standard practice, this is significantly more widespread in the USA than in the UK[xxii] where we are aware of no neonatal units with established universal psychosocial screening programmes. Our work (Evans et al., in press) is the first example published in the UK and demonstrates that a) the level of unassessed need is high; b) universal psychosocial screening significantly increases the identification of families for whom psychological support is indicated during a neonatal admission, and c) that it must also be underpinned by adequate capacity within the neonatal psychological service to meet this demand.

Where need is identified, psychological input can support a range of areas of outcomes at multiple levels, including supporting:

- Neuroprotective care of infants
- Parent-infant relationships (and therefore longer term attachment and developmental outcomes)
- Parental mental health (for both parents),
- Family relationships, including psychological support for siblings

Embedded neonatal psychological care provides a different but complementary service to perinatal or maternal mental health services. Having a specialist psychological professional embedded in the MDT allows for the development of psychologically informed care across the

system; reduces the barriers to acces; offers a holistic service to whoever in the family needs it (rather than being focused solely on mothers' mental health) and gives families the experience of being truly understood by someone who understands the environment and the journey of neonatal care.

The neonatal psychological support offer also needs to include follow up, and to provide this systemically for babies and families (rather than focusing just on baby's neurodevelopment). Families need support from qualified psychological professionals with experience in neonatal care when they are struggling with health- or admission-related issues post discharge. MDT teams similarly need someone bringing the systemic and psychological lens to outreach and follow up activities. This model of Clinical Health Psychology is well established in other specialities (e.g. oncology, stroke, chronic pain) where patients are supported by multi-disciplinary teams that have the capacity to promote an integrated approach to physical and psychological care.

Staff

Psychological professionals work beyond the infant and family, providing support and interventions to staff and managers. Trust-wide staff support services are useful, but a psychological professional embedded in the unit MDT can provide both immediate and bespoke support with an understanding of the complex environment and multiple stressors (highly technical role, sick babies, stressed parents, large complex MDT). They can offer support at a number of levels, including:

- Training to help staff understand the needs of themselves, their colleagues, babies and families
- Reflective practice spaces to help carry the emotional impact of the work

- Consultation to recognise the psychological needs of individual families, helping both to improve care but also to reduce the impact of caring for parents whose emotional or behavioural responses might be hard to carry
- Individual support to help them find ways to manage the impact of the work, with the option for onward referral to staff support services as needed.

Well supported staff are more present (less likely to be off sick), more productive and more able to be compassionate. This directly impacts the quality of care that infants and their families receive[xxiii].

Conclusion

We highlight neonatal experiences as a higher risk for post traumatic consequences for the baby, family and the wider MDT. These experiences disproportionately affect marginalised families, perpetuating health inequalities.

Currently, there are no units in the UK that are close to meeting staffing standards for psychological professionals. Across the 10 networks of England, psychological staffing falls between 13-35% of recommended standards, with an average of 25% (data provided to NHSE following Ockenden funding, 2023). This results in significant gaps in the care provided. The inadequate psychological support available for babies, families and staff reduces the quality of care provided and increases their vulnerability to poorer longer term outcomes. Inevitably, this has a longer term cost implication both in terms of human impact and to the demands on, and costs to, NHS and social care services over the infant and family's lifetime.

We recommend:

- Establishing embedded specialist neonatal psychological support in line with the Neonatal Critical Care Review[xxiv] and Getting It Right First

Time[xxv] reports and the new NHSE Neonatal Service Specification[XX] to provide the support needed to promote best outcomes for all those affected, but particularly babies and their parents[xix].

- Scoping and developing appropriate resources to meet the antenatal and post discharge (follow-up) psychological needs of neonatal babies and families to ensure that their additional needs are mitigated in the longer term.

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