

Dr Rachel Collum, Lady Sarra Hoy - Written evidence (PRT0031)

The authors

Dr Rachel Collum is a lecturer in Psychology at the University of Sunderland. Her research interests relate to promoting and improving Family Integrated Care for neonatal families whilst in hospital and beyond, across the lifespan. She is also Chair of the Northern Neonatal Network Parent Advisory Group and Family Advocacy and Support lead on the British Association of Perinatal Medicine Executive Committee.

Lady Sarra Hoy is a trained lawyer and founder of a neonatal research community interest company which aims to fund and share research to improve care and outcomes for neonatal patients. She is an ambassador for Bliss, the UK's largest neonatal charity and has supported parents of premature babies and children for almost ten years.

Both Rachel and Sarra have lived experience of parenting babies born pre-term: Both our babies were born at 29 weeks gestation and needed significant care on their respective neonatal units. Whilst both children have gone on to thrive, we have observed a range of developmental and social challenges in our children that prompted our curiosity in exploring if these issues were consistent in other children born pre-term. This has led to the current work and the evidence outlined below.

Overview

The Preterm Birth Committee was appointed to consider the prevention, and consequences, of preterm birth in England. An aim is to identify priority areas of intervention and further research. We argue here that one of these priority areas should be awareness and support of and for the impacts of prematurity in children who are considered 'healthy' and subsequently discharged from follow-up services by age 2 (or earlier). Whilst this cohort of children do not meet thresholds for any formal

diagnoses, the evidence outlined here clearly points to the prevalence of 'milder' or 'non-standardized' facets of prematurity of which parents would benefit from both peer and professional support.

We have both individually and collectively spoken to many parents following their neonatal experiences. We are aware of what a challenge the committee faces when attempting to address such a broad wide-ranging topic.

We wish to highlight from our own evidence that the impact of prematurity does not end upon discharge from a neonatal unit. An increased awareness of the long-term consequences of preterm birth is required to fashion policies to support these families as **part** of a wider policy to support improvement in the quality of care.

For the purposes of our report, we ask the Committee to prioritize additional intervention, support and research in supporting families and babies after discharge until school age, at which point we support the recommendations set out by Bliss and The Smallest Things in their evidence.

'Parenting a Premie' Project

In spring 2023, we conducted an online focus group with 5 mothers of babies born pre-term whose children had either never received follow-up after being discharged from the neonatal unit (1 family) or who had been discharged from follow-up services by 2 years of age (4 families). The children of the mothers interviewed ranged from 6-14 years and there were two sets of twins. The interviews were designed to be very open in order to explore the range of lived experiences of parenting a child born pre-term. Therefore, the themes that emerged were driven by the conversations between the mothers and not a direct response to specific questions. This makes the uniformity of the themes outlined below more striking.

What Happens After Neonatal Discharge?

Preterm birth can have a major impact on a parent, regardless of which gestation the baby was born or the duration of their neonatal stay. This impact often starts only after discharge from hospital. From our interviews with parents, whilst each and every story is different, they all say the same about the impact a neonatal stay has. Mothers in particular often feel isolated, unsupported and scared. Crucially from our interviews, when the individual stories are collated, the collective voice from parents calls for additional support after leaving the unit with their baby.

From the authors' personal experiences, we understand how difficult it can be for professionals to connect with parents whilst on a unit. It can be difficult to concentrate, read materials and take in new information whilst trying to care for your baby in a very clinical, alien environment, where fear and worry is paramount. This is why it is important to make efforts to engage with parents of newly discharged babies once families are settled in their home environments and have had time to begin to process their trauma, to develop a relationship to assist guiding them through the first few years. Flacking, Errald & Starrin, (2007) note that mothers report a "pendulum" of emotional experiences following discharge from the neonatal unit. In an intervention to support parents following neonatal discharge, Huang et al., (2023) found an increased/improved parenting sense of competence and parental care ability along with lower depression scores in the intervention group. This highlights the need for supported transitions to home and beyond.

Whilst in neonatal care, parents have the benefit and reassurance, to some extent, of medical professionals. Once discharged home, they no longer fall within the protective zone of the neonatal unit which they had come to know so well. Instead, they are left to come to terms and cope with the transition home, often with a baby who remains medically

vulnerable. One of our mothers commented that **"I was looking for something wrong all the time in the beginning"** whilst another articulated the strong sense of not having anyone to validate or reassure their concerns anymore: **"...no one was actually a point of reference to say, well, actually, that's a reasonable thing to consider for your babies."** It is evident here that the burden on a parent of a preterm child is profound as they monitor their child at home, particularly when we consider the impact the intense neonatal experience has had. With no more clinical guidance parents are left to navigate these years alone. It can be hard to know where to look for advice.

One main theme that has come across in our work is how often it comes down to parents to educate the professionals they deal with outside of a neonatal or paediatric setting, for example GPs, health visitors, schools, nurseries, etc. There is almost a role-reversal in which parents find themselves having to explain and advocate for their children: **"...once you're discharged, you're constantly fighting for your child. You're constantly fighting for the right support, and suddenly you find your voice and you make your voice really loud to get the support that you need for your child."** Baraldi et al., (2020) conducted qualitative research comparing families who had received post-discharge support and found three emerging themes around changing family dynamics, inner parent states and child-related worries, showing the breadth of concerns that a parent of a baby born pre-term continues to have.

Health visitors often have little to no experience of premature babies, perhaps never having spent any time inside a neonatal unit. Unwarranted pressure can be put on mothers by professionals without full understanding, for example with growth charts "*...there's moments where you can see the baby is not getting the care that you would like them to have...*" Support may be available from a GP, but again the expertise cannot be compared to that of someone with lived experience or professional guidance. It is often the case that families find themselves educating health professionals, health visitors and GPs about prematurity. Breathing difficulties and feeding are two examples that come up regularly, where specialised assistance is required. It should not be for mothers to educate or challenge health professionals who are trying to rely on incorrect information.

Friends & family, who may have no experience of prematurity, want to reassure parents with throw away phrases such as "But's he's better now!"... "they all catch up in the end". With a lack of understanding, despite well-meaning intentions, this invalidates and threatens to diminish the difficulties faced by these parents. Evidence from Johnson & Marlow (2017) indicates premature children do not all catch up and may face additional challenges. It is not acceptable for parents to navigate this alone without support. The value of peer support cannot be underestimated and this was a strong theme from our interviews: "***That reassurance is what I would try and pass on to others...***". Mothers spoke about struggling to process emotions like envy and guilt and commented on how intimidating and alienating 'normal' baby groups were because those parents didn't understand. "***I felt I never really had a peer group***". Kang & Cho (2021) conducted a scoping review of 15 papers looking at long-term follow-up and found only 6% of the research focused on issues for parents and families; the majority were all around

standardized and medical impacts, highlighting the need to shine more of a spotlight on the importance of peer support,

What Can We Do?

Intervention and support at discharge until at least the early years would help to alleviate this burden and distress. This would lead into early years professionals taking up the baton of support, as advocated by The Smallest Things Charity.

Our evidence suggests parents require more structured support at home upon discharge. We discuss suggestions below. If we bridge this gap in support, it would:

- I. Assist with continued parental and baby bonding, essential to the ongoing building of the family unit, feeding, eating and sleeping.
"...you know it wasn't love at first sight. It was a slow burner."
- II. Assist in the processing and healing from the traumatic experience of having a very ill baby.
- III. Support the mental health of both the mother and father. For example, many mothers report hypervigilance ("**...And then one day somebody said to me, you're not overprotective, you're protective. And that's your job.**") and there are increased incidences of postnatal depression for mothers and fathers of preterm babies (Genova et al., 2022). Postnatal care and psychological support for women who have given birth preterm can improve outcomes for babies and parents (Yoldaş et al., 2020). With structured support outside of the neonatal unit, we can reduce the impact of such consequences. This would also result in less pressure being put on GP services. This in turn would support parents in returning to work and improved economic benefits.

We propose the following to bridge the gap between neonatal discharge and early years support:

CARE

Communication and Connection

Acknowledgement

Reassurance and Expertise

Communication and Connection

Facilitation to join peer groups in the local area. Online groups would be of particular benefit here to maximise the possibility of mother and baby joining discussions. Peer led support groups allow exchange of information and essential support to reduce feelings of isolation and depression (Jones et al., 2014). Access for all is important to ensure ethnic and socio-economic inequality. Groups should offer information, allowing a platform to share support via a trusted source such as Bliss, which also has different language resources to ensure access for all.

Acknowledgement

It is important to recognise the neonatal journey doesn't finish upon discharge. The existence of a scheme such as this recognises these babies and families as being in need of additional support to navigate the range and complexity of challenges that come with prematurity. In this way, instead of reinforcing feelings of isolation, it forms a community network. Instead of yet another circumstance where "the normal rules don't apply" this will provide support, show understanding and empathy. Rather than parents feeling they have to 'battle' for the correct support

for their child, as the mothers we interviewed often described, signposting and support will be available.

Reassurance and Expertise

We argue for the provision of Specialist Health Visitors who have been trained, identified and assigned to families recently discharged from neonatal units. These health visitors should have experience and training such as the Neonatal Ambassador Training pilot offered by the Institute of Health Visitors. It should not be for parents to educate health professionals.

Summary:

To conclude, we submit the above evidence to add weight to the discussion that prematurity does not end at neonatal discharge. Even, or especially, in babies who are deemed medically 'healthy' enough to be discharged from follow-up services, the emotional, family and social dynamics of prematurity continue into the home and across a child's development. There is currently a gap in support for families once they have transitioned to home until they might access early years services and we must do more to utilize the power of peer support and specialist professional training to mitigate the feelings of isolation and uncertainty that can inhabit their lives. Following the CARE pathway will go a long way to acknowledging and responding to the parent voices of babies born pre-term.

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