Employment Rights Bill Submission



Written evidence submitted by Bliss (ERB34)

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Bliss is the UK charity that champions the right of every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.

Introduction

1 in 7 babies born in the UK is born needing neonatal care. Neonatal care is the type of hospital care that a baby receives if they are born unwell. Babies are admitted to neonatal care shortly after birth, either because they have been born prematurely (before 37 weeks of pregnancy) or at full term but sick. For example, they might have an infection or a genetic condition.

These babies are among the most vulnerable patients cared for in the NHS: they may spend days, weeks, and in some cases months in hospital. For parents of these babies, the experience is lifealtering. Rather than taking their baby or babies home shortly after birth, they are admitted to a specialist hospital unit to receive care which ensures they have the best possible chance of survival and quality of life.

Starting in April 2025, the Government will introduce a new statutory right to Neonatal Care Leave and Pay. This will be in addition to existing parental leave rights and recognises that parents of a baby receiving hospital care need paid time away from work to take care of them. Both parents of a baby in neonatal care will each be entitled to up to 12 weeks of statutory leave and pay. Neonatal care 'leave' will be a day one right, however, the 'pay' element will not be. With the current 26-week minimum service requirement for paid parental leave rights, approximately 3,200 parents will be entitled to neonatal care leave but not pay.

Bliss recommends that neonatal care pay become a day-one right, along with other types of parental leave, as the unpredictability of premature or sick births leaves newly employed parents facing severe financial strain and stress if forced to take unpaid leave. Without paid leave, fathers and partners must choose between working or being crucial partners in their baby's care—harming family wellbeing and potentially worsening health outcomes for their child. If neonatal care pay is made a day-one right, neonatal care leave is more likely to be taken up, particularly by parents who are on a lower income.

Key issues and findings from Bliss' work

The primary reason parents cannot take time away from work when their baby is in neonatal care is due to financial constraints. Therefore, without the paid element of neonatal care leave, the minimum service requirement will force many parents who are entitled to take additional leave to return to work before they and their babies are ready. The cost of having a baby in neonatal care is high: Bliss research has shown that families typically face an additional average cost of £405 per

week throughout their baby's neonatal stay¹. In our survey, parents on lower incomes were less likely to feel they could take time away from work than those on higher incomes. These parents need additional support to ensure they can spend time on the unit and be involved in their baby's care. We asked parents what type of support they would have needed to take time away from work and the most prominent answer was financial support.

Neonatal services in the UK strive to achieve family integrated care, promoting a culture of partnership between families and staff. This is crucial as research underscores the positive outcomes of parental partnership in care for babies, including improved infant reflexes at term and better gross motor development at four to five years². However, delivering family integrated care relies on parents being supported to be present on the neonatal unit which is particularly difficult for fathers and non-birthing mothers who don't have access to paid parental leave and must return to work while their baby is unwell.

"I wanted to contribute more to decisions that were made about his care. I could have supported my family in a more meaningful way than money."

Newly employed father whose premature baby spent over 12 weeks in hospital.

Parents being unable to participate in their baby's hands-on care and decision-making leads to parents feeling disconnected from their baby's care journey. Not being involved in hands-on care can result in parents feeling out of sync with the day-to-day realities of their baby's condition. This detachment not only affects their emotional bond with their baby but also undermines their sense of confidence in providing care. Moreover, missing critical moments like medical updates, milestones in recovery, or witnessing their baby's first feed or bath can weigh heavily on parents. Dads and non-birthing parents often rely on their partner, who may be more present, to relay updates second-hand, which compounds their stress and guilt.

Having a premature baby can have serious psychological consequences for parents⁴. Research has shown that up to 50% of parents whose babies received neonatal care experience Post Traumatic Stress Disorder and higher rates of anxiety and depression⁵. Findings from a Bliss survey highlighted the negative impact that not having the right employment support can have on this already heightened risk. Balancing the demands of work with caring responsibilities can be incredibly stressful and overwhelming. Parents may struggle to meet both sets of responsibilities, compounding feelings of stress and anxiety.

"I was having headaches and stomach palpitations every day. I was waking up sick. I nearly went into a car accident. Now I'm off sick [from work] at the minute because you can't do both."

Newly employed father whose premature baby spent 6 weeks in hospital.

Recommendation

The Government must amend the Employment Rights Bill to include neonatal care pay entitlements as a day-one right

¹ Bliss briefing: Impact of cost-of-living crisis in neonatal care (Bliss, 2022)

² Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU (Treherne et al, 2017)

³ Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial (O'Brien et al, 2018)

⁴ Psychology Staffing on the Neonatal Unit (Neonatal Consultant Clinical Psychologists and ODN Psychology Leads, 2022)

⁵ Supporting mental healthcare in a maternity and neonatal setting (NHS, 2021)