

**Neonatal care through  
a young parent lens**

**Bliss**  
for babies born  
premature or sick

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## About Bliss

Bliss was founded in 1979 by a group of concerned parents who discovered that no hospital had all the equipment or the trained staff it needed to safely care for premature and sick babies.

Determined to do something, these volunteers formed a charity to give vulnerable babies the care they deserve. More than 40 years later, Bliss has grown into the UK's leading charity for babies born premature or sick. Bliss champions the right for 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.

## Methods

Across May and June 2021, Bliss surveyed parents aged under 25, seeking to understand their experiences of neonatal care. This included questions relating to information and support needs, involvement in their baby's care and the impact of their experiences on their finances, work and education. In total, 202 responses were included in this research.

Twelve parents also took part in semi-structured telephone interviews. Participants were selected to ensure a broad mix of demographics and experience including: age, gender, parents from different ethnic backgrounds, parents with disabilities, parents of twins and multiples and bereaved parents.

We set up an involvement group, with four young parent members, who met monthly and shaped every aspect of the project. Activities included shaping the project priorities, reviewing and revising survey and interview question drafts, co-creating the report and co-designing its recommendations.

## Acknowledgements

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Natalie Allsop, T'lise Gibbs-Ward, Bethany Williams, and Marc Williamson were our involvement group members. Their insights and support in co-creating this work have been invaluable. Bliss would also like to thank the parents who responded to our survey and took part in our interviews. It has been a privilege to hear their stories.



# Summary of findings

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The myth that young mothers are almost guaranteed to have healthy babies amplified the shock of the neonatal experience.



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Parents who needed psychological support were often unable to access it.



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21 per cent of young parents did not feel well supported by staff on neonatal units and some experienced age-related discrimination.



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55 per cent were not as involved in caregiving or decision-making as they wanted to be.



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Young parents in education or insecure work lost out on statutory leave and pay.

# Summary of findings

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59 per cent said information about neonatal care during pregnancy would have made them more confident.



Mothers' own care was compromised if they were receiving inpatient postnatal care and attending the neonatal unit at the same time.



26 per cent of young parents were living with family when their babies were born.



20 per cent of parents under 21 said they were in education when their babies were admitted to neonatal care, there is no guidance to ensure they get the right support.

# Introduction

Every year, around 100,000 babies are born premature or sick in the UK. Despite an increased risk of prematurity and neonatal mortality for babies born to mothers aged under 20<sup>i</sup>, to date there has been a lack of research into young parents' experiences of neonatal care. This project aims to understand the unique challenges that younger parents face when their baby is born premature or sick – and to identify what support, information and wider policy and service development is needed to remove or mitigate these.

This project has also been an opportunity for Bliss to work in partnership with young parents to identify how we can be more inclusive in the information and support that we offer, and how we can better advocate for the needs of younger families.

Our findings show that younger parents have many of the same stresses and anxieties as other parents when their baby needs hospital care after birth – but that these can be amplified by age-related discrimination, variation in family-centred care, reduced awareness of neonatal care, and challenges in juggling education and work.

## What do we already know?

Babies born to mothers aged under 20 are at a 75 per cent increased risk of neonatal death compared to mothers aged 30-34.<sup>ii</sup>

Young parents who are in the difficult and distressing position of having a baby in neonatal care are often facing a variety of other challenges, with individual risk factors for early pregnancy including family poverty, persistent school absence, and being looked after or a care leaver.<sup>iii</sup>

The fact that some young parents find it more difficult to navigate healthcare systems and require specialist support is widely recognised. The Local Government Association and Public Health England identified that, in 2018, children born to women under 20 were 63 per cent more likely to be living in poverty and three times more likely to suffer sudden infant death, while the mothers were a third less likely to initiate breastfeeding and half as likely to be breastfeeding at 6-8 weeks. They were also more likely to suffer poor mental health for up to three years after the birth.<sup>iv</sup>

The Family Nurse Partnership (FNP) scheme has provided tailored support to young parents to support the transition to parenthood and accessing healthcare. For families using the programme, the impact has been significant: 64 per cent of FNP clients initiate breastfeeding and 81 per cent of FNP babies meet the same developmental milestones as their peers at fourteen months.<sup>v</sup>

<sup>i</sup>Marvin-Dowle, K. and Soltani, H. (2020) A comparison of neonatal outcomes between adolescent and adult mothers in developed countries: A systematic review and meta-analysis, *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 10(6): 100109.

<sup>ii</sup>MBRAACE-UK (2021) Perinatal Mortality Surveillance Report UK Perinatal Deaths for Births from January to December 2019.

<sup>iii</sup>Public Health England and Local Government Association. (2016) A framework for supporting teenage mothers and young fathers.

<sup>iv</sup>Local Government Association and Public Health England. (2018) Good progress but more to do: Teenage pregnancy and young parents.

<sup>v</sup>Family Nurse Partnership (2021) What Family Nurse Partnership Delivers.

# Preparing young parents for a neonatal admission



**The myth that young mothers are almost guaranteed to have healthy babies amplified the shock of the neonatal experience.**

Young parents described a pervasive belief that mothers who are young and healthy are almost guaranteed to have healthy babies, and that everything will go smoothly. While babies born to healthy parents, and to parents of all ages, are sometimes admitted to neonatal care, expectant younger parents were not necessarily aware of this.

*"I'd always been told, 'You are low risk; there is nothing to worry about', so I thought, *oh I should be absolutely fine...* I just felt really like, *I don't know what I'm doing here* because I also thought that, when I looked into it more, pre-eclampsia only happens to older women or if you are overweight or diabetic or something like that. I thought, *why am I in here because there's nothing wrong with me?* I just didn't understand it."* - **interviewee who was 23 when her baby was born**

*"I was fit and healthy... I didn't know anything about premature babies before having him either. I just thought, [with] your first...you are always late so I didn't have any worries thinking that something would happen. Then, with my second, I always thought, *oh because there was no reason technically, I should get to full term*, and then obviously it happened again."* - **interviewee who was 21 and 23 when her babies were born**

For some young parents, this led to acute distress, questioning why their baby had been born premature or sick. Sometimes there were also feelings of guilt and worries that their baby may have been premature or sick because of something they had done.

*"I said to my mum, 'I'm not doing this anymore. I can't do it. I don't want to do it anymore... I don't want to be a mum... I've had enough.' I was like, 'Why do I have to go through it when through my pregnancy I'd done nothing wrong?'... At first I felt really guilty saying it, but you see these people take drugs and drink their whole way through their pregnancy and their child is absolutely fine. So, you do think, *why has this happened to me? All I've done is nothing but try and keep my baby safe.*"* - **interviewee who was 19 when her baby was born**

The fact that neonatal admissions were so unexpected for young parents contributed to their feeling underprepared. There was a strong theme of numerous missed opportunities to explain to young parents about neonatal care before their babies were admitted. Some did not know what a neonatal unit was and most had no idea what it would be like, making it more difficult for them to adjust to life on the unit.

*"I felt really unprepared, and I didn't really know anyone that had been in that situation before either, whereas I guess older people would have seen people in these situations before and have other children."* - **interviewee who was 21 when her baby was born**

*"You don't ever expect you or your baby to end up in there really... You don't know so much about neonatal units. I mean, I don't think my partner knew what neonatal was, or [what it] did for babies, before we were in there. So, getting to grips with all the medical terms and all of that is just something completely new."* - **interviewee who was 20 when her twins were born**

A few young parents benefited from visiting a neonatal unit before their baby was born, which helped to prepare them. Similarly, a member of the involvement group described being shown a resuscitaire when visiting the maternity suite, which she found reassuring, knowing that the hospital was equipped for any problems that might arise. When her baby was resuscitated, she felt less distressed because she understood what was happening. However, she had not been told about the hospital's neonatal unit so, when her baby was moved there, it was extremely frightening and she felt as if she had only been given half the information that she needed: "like the rug had been pulled from under my feet."

Young parents called strongly for more information about neonatal care during pregnancy. Overall, 59 per cent of survey respondents identified this as something that would have helped them to feel more confident when their baby was born, the most popular of all options presented. This was echoed by our involvement group who were unanimous in calling for antenatal information about neonatal care when asked what one thing they would change about their neonatal experience.

**"I think that neonatal possibilities and when/how there are any chances of a premature baby discussions should be emphasised during pregnancy." - survey respondent aged 19-21 when her baby was born**



# Young parents' involvement in their babies' care



**55 per cent were not as involved in caregiving or decision-making as they wanted to be.**

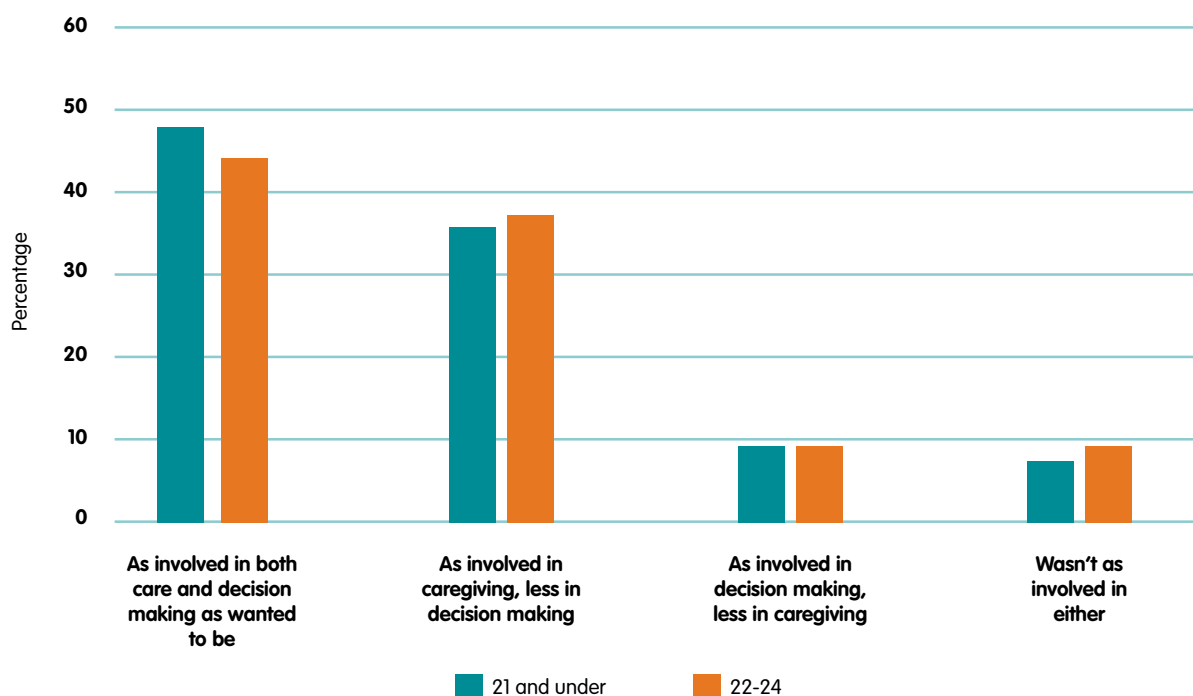
It is essential that parents are supported and empowered to take the lead in delivering their baby's care on the neonatal unit so that babies, and their families, have the very best outcomes. High levels of hands-on care delivery have been linked to improved breastfeeding rates, increased weight gain for babies and improved neurodevelopmental outcomes.<sup>vi vii</sup> It also promotes attachment, bonding and improves parental confidence.<sup>viii ix x</sup>

## Care and decision-making

55 per cent of survey respondents said that they were not as involved in either decision-making or caregiving for their babies as they wanted to be.

Our research found that young parents felt more confident providing hands-on care to their baby compared to decision-making. Young parents felt that confidence in providing cares – such as feeding, changing, bathing and supporting the clinical care of their baby – improved over time. In terms of decision-making, some parents felt unable to ask questions, seek clarification, or challenge decisions they disagreed with. Neonatal staff - who were sometimes much older- could be viewed as authority figures who could not be questioned or challenged.

## How involved were you in the care and decision making for your baby or babies?



<sup>vi</sup>O'Brien et al (2018) Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial, *Lancet Child Adolesc Health*, 2(4):245-254

<sup>vii</sup>Pineda et al (2017) Parent participation in the neonatal intensive care unit: Predictors and relationships to neurobehavior and developmental outcomes, *Early Human Development*, 117:32-38

<sup>viii</sup>Flacking et al (2012) Closeness and Separation in neonatal intensive care, *Acta Paediatr*, 101(10): 1032-1037

<sup>ix</sup>Treherne et al (2017) Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU, *Journal of Obstetric, Gynecological and Neonatal Nursing*, 46(5):737-747

<sup>x</sup>O'Brien et al. (2018) Effectiveness of Family Integrated Care in neonatal intensive care units

"I did not have the confidence to press for more information to grasp a better understanding."  
- **survey respondent who was 16-18 when her baby was born**

"I wasn't very confident... I was terrified, traumatised, and I used to think *a doctor is a doctor, like, you don't question them*... I didn't feel like I could contribute as during the last seven days my daughter was off everything, we just needed to establish (breastfeeding). I wanted to go home with her but she hadn't 'gained weight' so we weren't allowed. I felt like we were imprisoned (confined in one room) and I think this contributed to me not feeling like her mum. Because I wasn't in charge; they were in control. And this affected me a lot with bonding in the beginning." - **survey respondent aged 19-21 when her baby was born**

"Straight away, within the first day, we were doing nappies and we would do their feeds with the syringes and stuff because they didn't have bottles for a long time because their swallowing reflexes were so underdeveloped at that point... It did get to a point where we knew what we were doing and we knew how to get the gas out of their tummy with the syringes and if we had them out the incubators, we knew what to watch out for, if their SATs started dropping and just things like that which at the start you have no idea [about]." - **interviewee who was 21 when her twins were born**

Due to small numbers of fathers responding to the survey, it was not possible to compare the quantitative data for parental involvement between mothers and fathers. However, both the survey comments and interviews highlighted barriers to fathers' presence and participation on neonatal units. This is partly because of insufficient paternity leave and pay for fathers whose babies are admitted to neonatal care, as described below, but it also reflects young fathers' perception that neonatal staff often viewed mothers as the primary parent. This is in keeping with previous research, which has found that staff attitudes toward fathers on neonatal units can be disparaging and subsequently fathers can be ignored or pushed aside.<sup>xi xii xiii</sup>

"They would ask my partner on all decisions." - **survey respondent aged 19-21 when his baby was born**

"It felt quite difficult because the medical team were more focused on the mother rather than both of us together... Any question was directed at her... So, it's kind as if they were forgetting I was there or acknowledging me, as if I didn't really have a say. So, I was a bit distressed about that." - **interviewee who was 22 when his twins were born**

Our findings show a lack of consistency in how neonatal units involved young parents in caregiving. Young parents identified a range of barriers to being involved, such as: feeling uncertain of how to do baby care safely, fear of being watched and judged by neonatal staff, and not knowing where baby care items were kept on the neonatal unit. Some young parents did not get the support and guidance that they needed to do hands-on care for their babies, including inadequate feeding support.

"I felt like everyone was watching me and judging me as a parent. I was a first-time mum and wasn't sure how to change a nappy, let alone on 3lb twins in incubators covered in wires and tubes."  
- **survey respondent aged 22-24 when her twins were born**

"I wish I had received more support around breastfeeding when my baby was in NICU. We missed out due to my anxiety around privacy and it meant that, six weeks after he was born, he was still not breastfeeding." - **survey respondent aged 22-24 when her baby was born**

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<sup>xi</sup>Hugill, K. (2014) Father-staff relationships in a neonatal unit: being judged and judging, Parental Support, 10(4):128-131

<sup>xii</sup>Fisher, D. et al (2018) Fathers in neonatal units: Improving infant health by supporting the baby-father bond and mother-father coparenting, Journal of Neonatal Nursing, 24(6): 306-12

<sup>xiii</sup>Hollywood, M. and Hollywood, E. (2011) The lived experiences of fathers of a premature baby on a neonatal intensive care unit, Journal of Neonatal Nursing, 17(1): 32-40

## Communication

It is vital that information is communicated clearly to young parents so that they can contribute meaningfully to their baby's care and decision-making.

While most young parents felt neonatal doctors and nurses explained things well, one in five reflected that communication was often unclear. Some young parents felt that they were excluded from discussions around their babies' care because they were assumed to be incapable of understanding or contributing. Others felt that they were included but were unable to contribute because staff were using inaccessible medical language. The quality of communication also often varied between individual staff members.

"I feel, as a young adult, they need to try and reword things in easier terms. I felt they messed up telling me one thing then another. Still to this day I'm not sure what they did to my daughter." - **survey respondent aged 22-24 when her baby was born**

"Feeling excluded from my son's care, under what I felt was the assumption I wouldn't understand it, is one of the most mentally challenging parts of his NICU journey. I felt, as a parent, once we got home that I needed to prove I knew how to support this tiny, poorly baby." - **survey respondent aged 16-18 when her baby was born**

"I felt like the doctors used a lot of big words whereas the nurses were easier to understand (basically translated what the doctors said)." - **survey respondent aged 19-21 when her baby was born**

## Working with maternity services



**Mothers' own care was compromised if they were receiving inpatient postnatal care and attending the neonatal unit at the same time.**

Many young mothers whose babies are admitted to neonatal care also need inpatient postnatal care. A lack of joined-up working between neonatal and maternity wards was identified as a significant barrier to parental involvement, as well as being highly stressful and causing unnecessary suffering. Poor communication between staff working on neonatal and maternity units resulted in young mothers' feeling uninformed and excluded, and not having the assistance they needed to be with their babies or participate in decisions around their care. The disjointed nature of services, which often worked to conflicting schedules, also meant that young mothers missed their own meals, medication or medical monitoring – forcing them to choose between their own care and caring for their babies.

**"Medication was a big problem in my opinion... When you get sent downstairs after you have the baby, they used to ring up the neonatal unit and tell me to come downstairs to get my medication, or I'd come downstairs and they just wouldn't have left me any dinner because I don't want to sit in an empty ward on my own listening to people and their babies... So I did end up missing dinners and medication rounds because it is just a big blur." - interviewee who was 20 when her twins were born**

**"It was difficult to schedule in the cares as they were always when meals were due. This meant quite a few times I had to choose between going to eat and my child." - survey respondent aged 22-24 when her baby was born**

While these issues are not specific to younger mothers, they were felt more intensely when girls and young women were younger than other mothers on the postnatal ward. Some felt that the other mothers were wondering what had happened and even assuming that, because of their age, they must be to blame for their babies' being taken away.

# Judgement and discrimination



**21 per cent of young parents did not feel well supported by staff on neonatal units and some experienced age-related discrimination.**

Young parents reported mixed perceptions of how they were viewed and treated whilst on the neonatal unit. While most young parents reported being well supported by staff, more than a fifth (21 per cent) said they were unsupported or felt neutral about the support they had received. Parents whose babies were transferred described very different staff attitudes at different hospitals, but there were also differing approaches from one individual to another within the same ward environment.

Sadly, age-related discrimination emerged as a strong theme of both the interviews and the survey. Where this occurred, it had a significant impact on young parents. It was particularly an issue for those aged under 20 but was experienced by parents up to 25.

**"I literally look about 16/17 so when I turned up on the ward, the amount of looks I got: 'Oh, she's had a baby. I bet it's something that she's done.'... Some people actually asked if I was 12." - interviewee who was 19 when her baby was born**

**"Even though I wasn't a teen mum, I was still a young mum, and even now at 26 I'm still the youngest mum at most baby groups and things like that. So, I do feel a bit alienated because everyone else has got their own little cliques and groups where I feel everyone is looking down thinking, 'Oh, what a young mum.'... People talk about teen mums but I still think there is a bit of stigma about young mums in general." - interviewee who had babies in neonatal care at 21 and 23**

Some young parents felt that they were considered less capable than other parents on the neonatal unit. In some cases, this severely affected their confidence.

**"I think sometimes people look down their noses at you without realising they are doing it. There was quite an obvious difference in how I was spoken to compared to how the other parents were spoken to. It was like they felt like they had to teach me what to do whereas they just expected everybody else to know." - 24 year old interviewee who has had three babies in neonatal care**

**"It was causing problems with [my partner] because we were both arguing, saying, 'Is it us? Are we doing enough? Are we not doing enough? Are we good enough as parents?' We really doubted ourselves. I thought the NICU experience was supposed to be nice but it really, really, really wasn't." - interviewee who was 16 when his baby was born**

When we discussed this issue in the involvement group, young parents felt that discrimination was not always intentional but was the result of unconscious bias and a lack of self-awareness around people's own prejudices. This was echoed in the assumptions that young parents felt were made about them:

**"My mum had to get involved and say, 'Look... she's not your average 19-year-old. She doesn't go out clubbing. She's not on the streets. She's very mature for her age.'" - interviewee who was 19 when her baby was born**



# Young parents' information and support needs



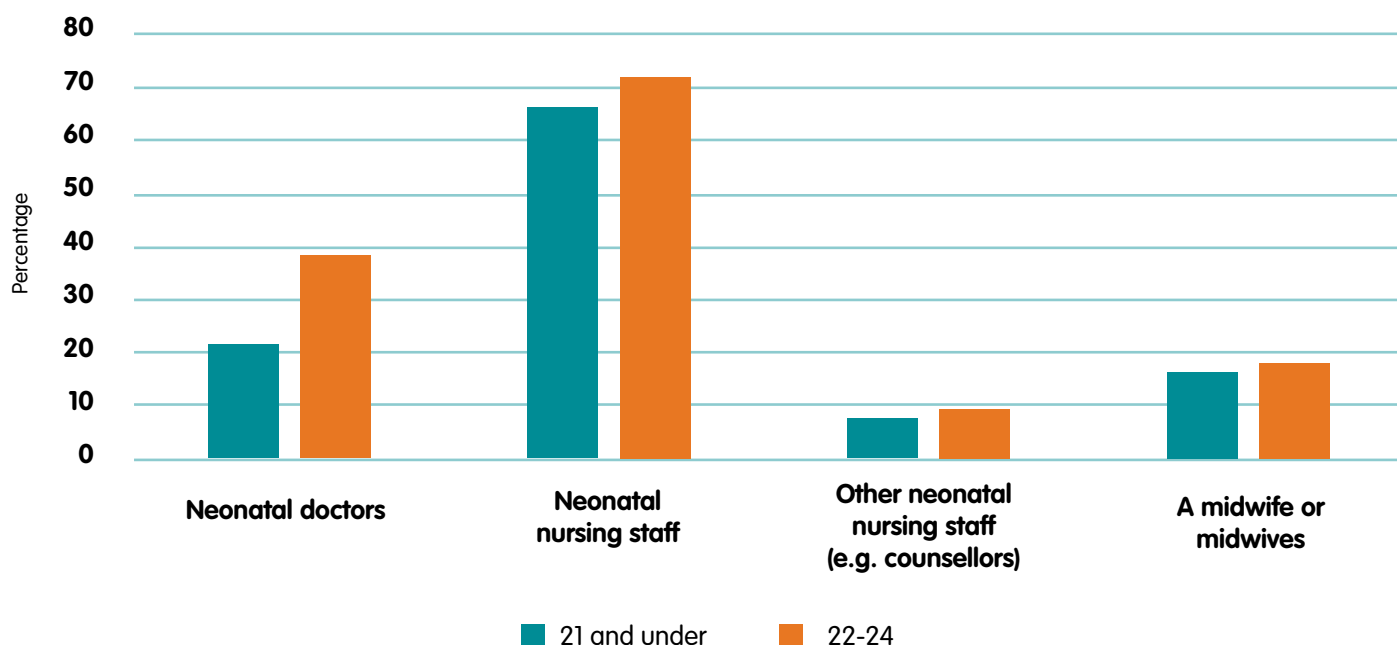
**59 per cent said information about neonatal care during pregnancy would have made them more confident.**

Information and support are key to ensuring that young parents can care for their babies effectively. Young parents felt strongly that more support from healthcare professionals would have improved their confidence, particularly at key points in their journey where there is often a lack of input, such as before admission to the neonatal unit and post-discharge.

Neonatal doctors play an important role in assessing a baby's clinical needs and agreeing the most appropriate care. It is important that they can provide young parents with the information and advice they need, as well as empower young parents to be involved in decision-making about their babies' care. Far fewer young parents identified neonatal doctors as people they would turn to, compared to neonatal nurses.

Young parents aged under 21 were less likely to turn to neonatal doctors or nurses for information and advice.

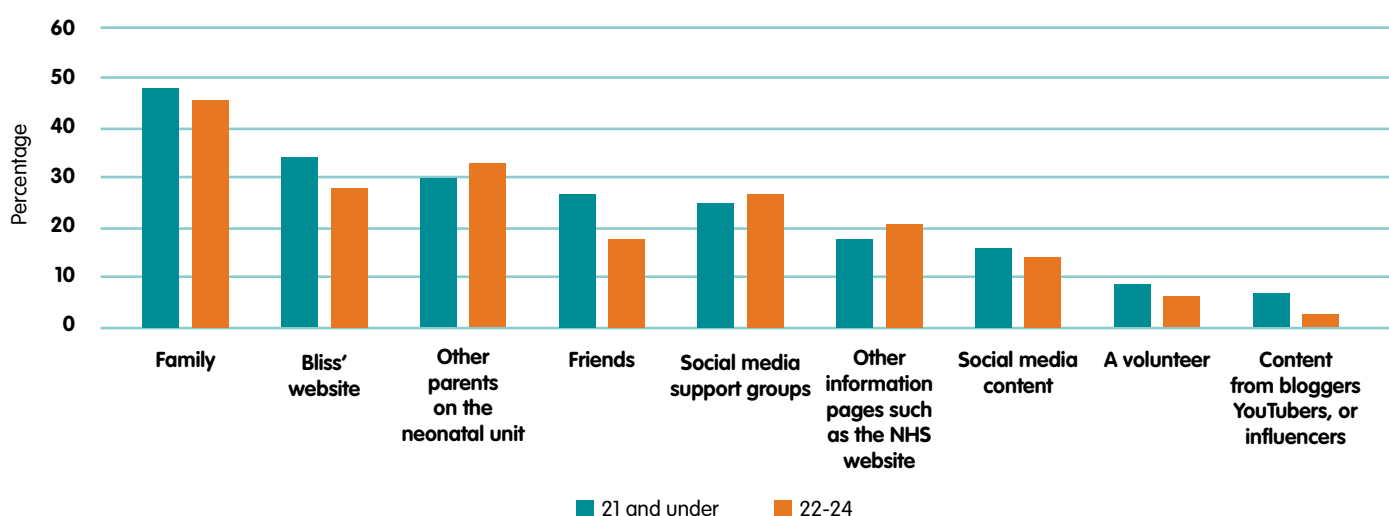
## Where did you turn for information and advice? (healthcare professionals only)



Our findings also show that there is no one-size-fits-all approach to making advice and support accessible to younger parents. While more than a third of young parents would have liked specific information tailored to younger parents, those aged under 21 were much more likely to value both peer support and online information tailored to their age group, compared to young parents aged 22-24 who generally favoured printed materials.

Young parents aged under 21 were much more likely to seek advice and information from less informed sources compared to parents aged 22-24, including their friends (38 per cent vs. 21 per cent) and bloggers, YouTubers or social media influencers (seven per cent vs. three per cent). This is important for both organisations like Bliss, and NHS neonatal service providers, to consider when reaching and tailoring support to younger families.

### Where did you turn for information and advice? (excluding healthcare professionals)



Unsurprisingly, there was significant overlap between where young parents sought information and advice and where they sought support, with neonatal nurses and their own parents identified as key sources of both support and guidance. It is common for parents to feel isolated with premature or sick babies, but this seemed to be enhanced for younger parents who were often the only ones amongst their friends having babies at all. In keeping with this, few young parents responding to our survey identified their friends as a source of support, though 22-24-year-olds were more than twice as likely to do so as parents aged 21 and under (12 per cent compared to five per cent).

*"I thought, I literally have no one to talk to that's gone through this and felt this way. So that was really hard... I just wanted to say about the support when you are in the NICU and also after, because the mental health side, I just think the support... needs to be a lot bigger and pushed."* - **interviewee who was 23 when her baby was born**

Although nearly a third of young parents turned to other young parents on the neonatal unit for information and advice, far fewer identified other parents as a source of support, suggesting that young parents can feel excluded from camaraderie amongst other parents on the unit. Only 16 per cent of 22-24-year-olds who responded to our survey identified other neonatal parents as a source of support, reducing to nine per cent for parents aged 21 or under.

*"I think I was very, very young when I had him, and I don't think people quite knew what to make of the situation... So it was easier to avoid me than ask what's gone on here."* - **interviewee who has had three babies in neonatal care, recalling her first experience aged 15**

# Grandparents' impact and involvement

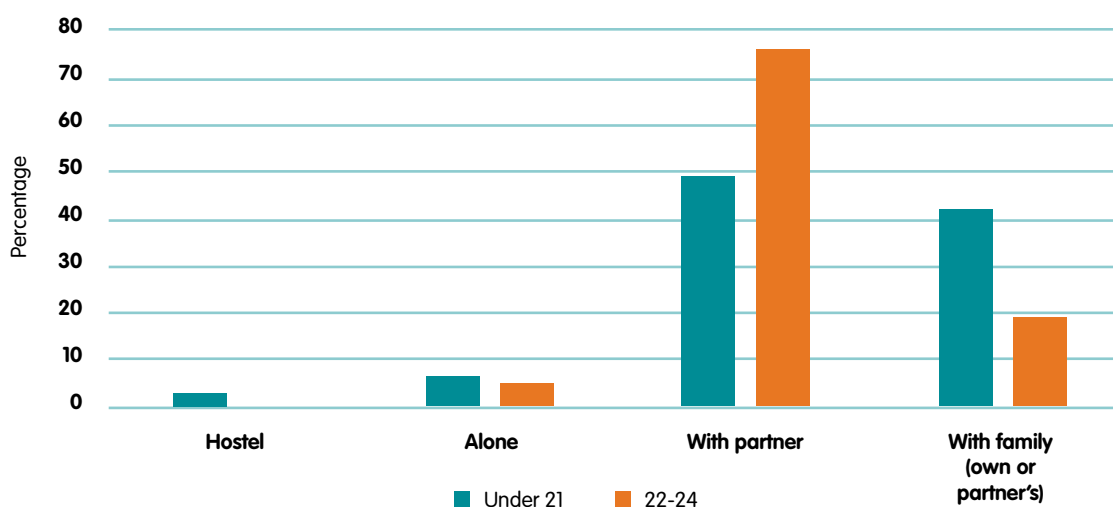


**26 per cent of young parents were living with family when their babies were born.**

Grandparents of sick or premature babies often play a significant role when parents are younger, providing a combination of financial, practical and emotional support. Although we know that some young people enter parenthood without trusted, consistent parental figures of their own,<sup>xiv</sup> most young parents who participated in this research were reliant on their own parents for support and valued those relationships enormously. It is important to consider how the experiences outlined in this report may be heightened for young parents who do not have a strong support system.

A quarter of young parents who responded to the survey were living with either their parents, their partner's parents or other family members at the time their baby or babies were born. Parents aged 21 or under were around twice as likely to live with family members, including either their own or their partner's parents, compared to parents who were 22-24 years old.

## Where were you living when your baby or babies were in neonatal care?



While most young parents identified their own parents or wider family as one of their main sources of support, parents aged 21 or under were much more likely to say their parents supported them most compared to those aged 22-24 (70 per cent vs. 54 per cent). This support could take the form of driving young parents to and from the hospital, cooking meals or packing lunches for them to take, helping them to navigate healthcare systems, and helping with baby care before and after discharge home. As a result, a neonatal admission can have a significant impact on the wider family.

**"I couldn't drive with my caesarean and my partner, he was at work. There was always someone around to take me to see the girls and just help me out with the sterilising of the pumping equipment and stuff." - interviewee who was 21 and living with her parents when her twins were born**

<sup>xiv</sup>Public Health England and Local Government Association. (2016) A framework for supporting teenage mothers and young fathers.

"My mum had to pay for petrol and the food... My mum has still got...a three-year-old and a ten-year-old at home... She'd drive up and then have to find childcare for them to support me because I literally had no one in the week. I'd be there on my own all the time... My mum felt obviously torn, trying to come helping me, supporting me because I'm on my own, but then obviously she had two young kids at home. Then my partner's parents would come up on the weekend and take us for dinner just so we could have that hour away." - **interviewee who was 19 and living with her own mother when her baby was born**

"My mum was driving three hours there and three hours back four times a week, cooking me food, paying for petrol and any other bits I needed, which left them skint." - **survey respondent who was aged 19-21 and living with a partner when her baby was born**

A significant challenge for young parents – particularly those aged under 21 – are neonatal unit policies which do not allow extensive visiting for wider families, or for a baby's parent to nominate an additional 'carer' if one parent is absent. This issue has been exacerbated by the COVID-19 pandemic and can deprive vulnerable young parents of a vital source of support.

"I was only 15 and his dad wasn't around... I understand why they did it because my mum wasn't his dad, but I had to sit in neonatal all day every day with my son on my own because my mum could only come up at grandparents' visiting times even though his dad wasn't around." - **interviewee who has had three babies in neonatal care, recalling her first experience**

# Young parents in education



**20 per cent of parents under 21 are in education when their babies are admitted to neonatal care, but there is no guidance to ensure they can take leave and get the right support.**

## Policy background

There is little guidance or policy around how schools and higher education institutions (HEIs) should support young people who become parents while studying. As a result, leave and support for student parents is highly variable.

## Schools

There is no national policy around leave and support for school-age parents whose babies need neonatal care. Guidance for supporting pregnant pupils is contained in Local Authority Guidance, *Ensuring a good education for children who cannot attend school because of health needs* (2013). The *Equality Act* (2010) renders it unlawful for schools to treat pupils less favourably because they are pregnant or have a baby.

There is no obligation for schools to allow paternity leave for school-age fathers. If the school, in consultation with the young father, feels it is appropriate, it is recommended that a teenage father should be allowed no more than ten days' authorised absence.

## Higher education institutions

The Equality Challenge Unit (ECU) report *student pregnancy and maternity: implications for higher education institutions* (2010) recommends that HEIs 'consider' developing a policy and procedures for supporting students during pregnancy and maternity, but there is no legal obligation for HEIs to have such a policy in place.<sup>xv</sup>

While the ECU recommend that HEIs support students to take maternity leave, paternity leave and leave for miscarriage or stillbirth, there are no equivalent recommendations about leave or support if a student's baby is born needing neonatal care.

Around ten per cent of survey respondents were studying at college or university when their babies were born, although there was a significant difference between parents aged under 21 and 22-24 (20 per cent vs. four per cent). It is unknown how many children and young people become parents while still in education each year in the UK.

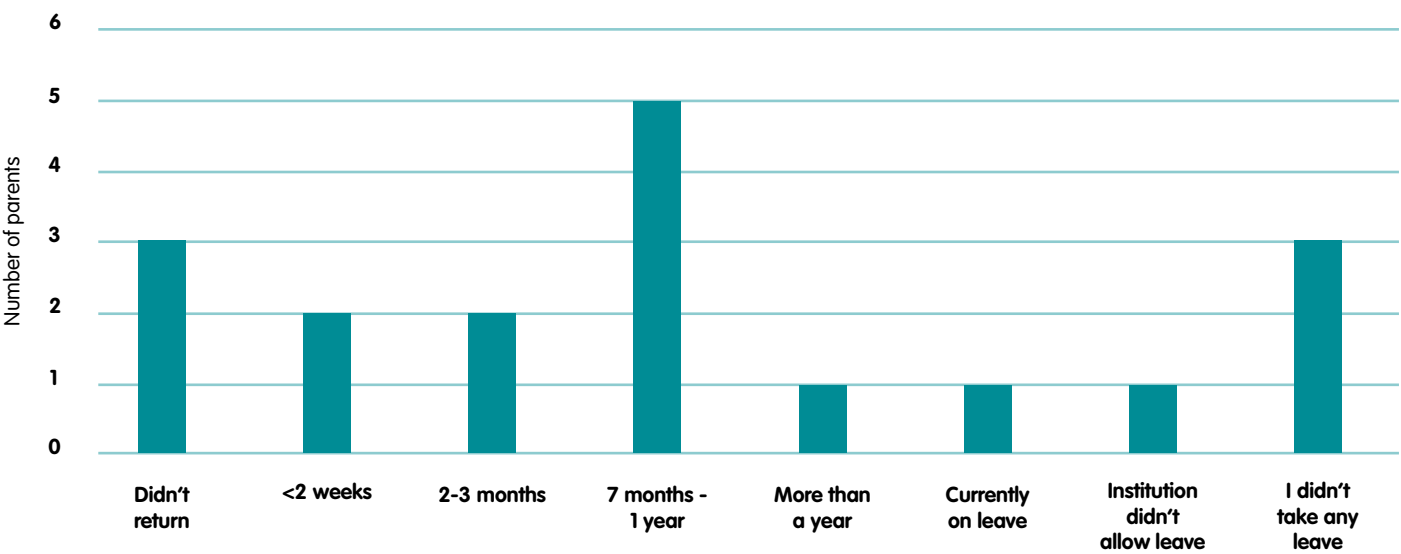
<sup>xv</sup>Equality Challenge Unit (2010) *Student pregnancy and maternity: implications for higher education institutions*.



18 survey respondents left details about how they managed their studies when their babies were in neonatal care. Most did not take an extended break from their studies, and some reported continuing to study while their baby was in hospital, often, astonishingly, meeting the same deadlines and expectations as their peers. This was also mirrored in our discussions with interviewees. For some, this was additional pressure, while others experienced it as a welcome distraction.

While numbers are small, those 18 respondents had a wide variety of experiences in terms of taking leave from their studies – varying from taking no time away from their studies at all, to leaving their studies altogether. The support parents received from their institution varied significantly too, though the majority (12 out of 17) reported that they had been well supported. A couple of respondents noted in the free-text comments that they didn’t tell their institution about their situation, and this was also true of one interviewee.

### Length of time taken away from studies



“I was still at school and obviously I didn’t expect him to come nine weeks early...I needed to step back from that because I needed to be there for him. But my school went, ‘No, you’re not taking a step back. You don’t need any time off. If you’re going to go, you’re gone.’ So, I still ended up having work sent home, this, that and the other, all day every day. They wanted me to complete the timetable that everyone else was completing at school... while I was still in the hospital with my son. So, if I’m honest, I think my mum filled most of the worksheets out on the sly and sent them back because I just couldn’t do it.” - **24 year old mother who has had three babies in neonatal care, recalling her first experience**

“I was at college studying... Obviously my mum informed them with what was happening, and they were a bit funny at first but as soon as they realised how serious it was, they were [supportive]. I had a laptop from them and just had to send work in by deadlines still. But we managed to get it done... I did it all on time, all my exams were in on time.” - **interviewee who was 19 when her baby was born**

# Young parents' work and finances



Young parents in education or insecure work  
lost out on statutory leave and pay.

## Policy background

There is a range of statutory parental leave and pay options available to parents when their baby is born including: Maternity Leave and Pay, Paternity Leave and Pay and Shared Parental Leave and Pay.<sup>xvi</sup>

To qualify for statutory leave and pay, parents must meet certain criteria, which varies between each statutory leave and pay policy. Qualifying criteria can include:

- Parents must be an employee (not a worker or self-employed). This is true for all statutory leave and pay.
- Parents must have worked for their employer for a certain length of time.
- To qualify for statutory pay, parents' wages will need to meet a minimum level.

Mothers who do not qualify for statutory maternity pay, are self-employed or have recently stopped working may be entitled to Maternity Allowance.

It is unknown what proportion of parents aged under 25 are entitled to statutory parental leave and pay. However, young parents are more likely to be precariously employed and so less likely to be eligible. The 2017 *Taylor Review of Modern Working Practices* found that people aged 16-24 account for one third of all zero hours contracts, and that 18 per cent of people on zero-hours contracts are also in full-time education.<sup>xvii</sup> Young people are also overrepresented workers within the 'gig' economy (broadly defined as short-term contracts or freelance work as opposed to permanent jobs) with nearly four in ten aged 18-29.<sup>xviii</sup>

When their babies were admitted to neonatal care, more than two-thirds of the young parents who responded to our survey were working full-time (55 per cent) or part-time (12 per cent), although this also reflects the fact that two-thirds (67 per cent) of respondents were aged 22-24. Parents aged 21 or under were more likely to be employed part-time (17 per cent) or unemployed (17 per cent), compared to parents aged 22-24 (ten per cent and 15 per cent respectively).

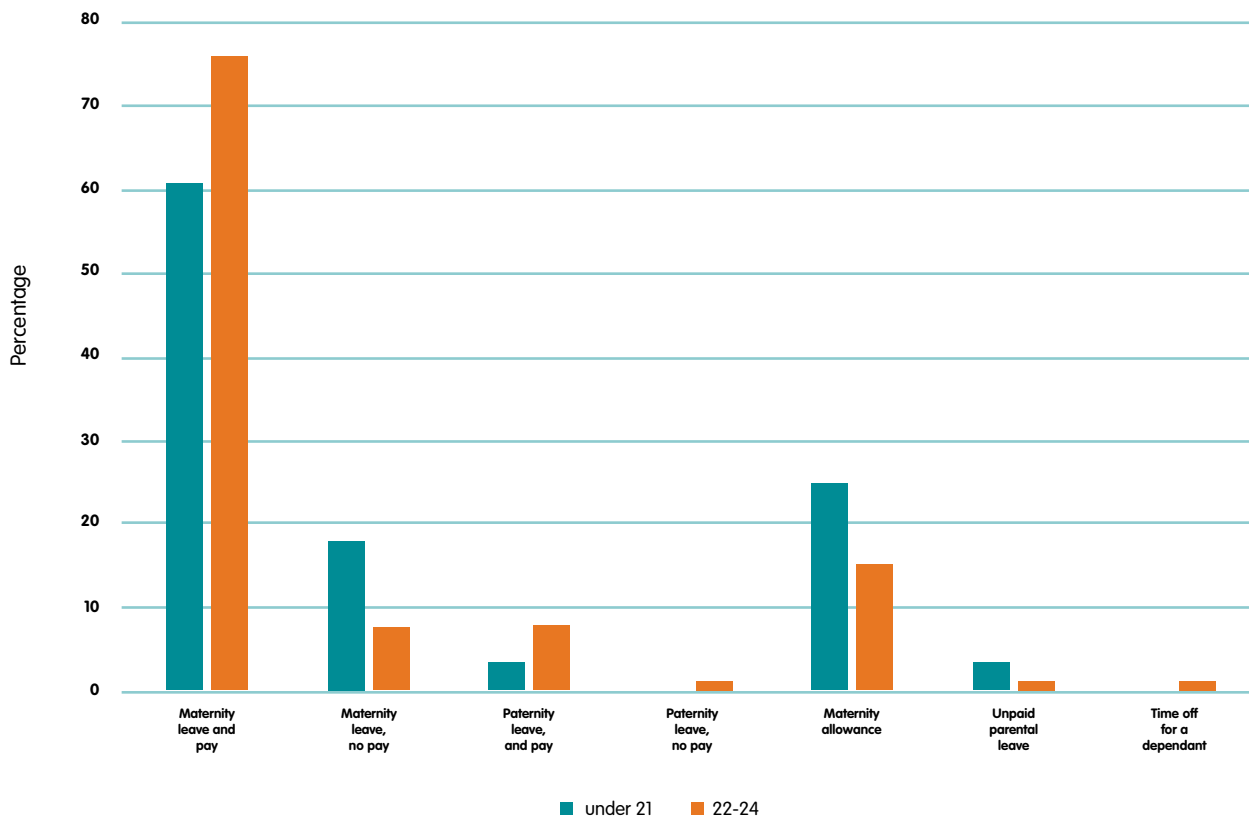
While numbers are small, our results suggest that parents under 21 years old were significantly less likely to be entitled to statutory leave and pay, and more likely to have taken some form of unpaid leave. Mothers aged under 21 were also more likely to use maternity allowance, suggesting that they had not met the requirements to qualify for statutory maternity pay.

<sup>xvi</sup>For more information about the qualifying criteria for statutory parental leave, please visit [gov.uk](https://www.gov.uk)

<sup>xvii</sup>Matthew Taylor (2017) *Good Work: The Taylor Review of Modern Working Practices*

<sup>xviii</sup>Matthew Taylor (2017) *Good Work*

## What type(s) of parental leave did you take?



"My partner was working but obviously he was only 20 years old... where he worked the pay wasn't great. Luckily, they said, 'You can have your paternity leave for two weeks. As soon as those two weeks were up you are coming back. No more time off.' ...So he missed quite a lot. He would come up every weekend and stay, after the two-week period, and obviously make the most of it with both of us." - **interviewee who was 19 when her baby was born**

"My partner, baby's dad, wasn't entitled to any paternity pay or leave from the beginning. This needs to change." - **survey respondent aged 22-24 when her baby was born**

For some young fathers, the lack of paternity leave – meaning that they either had to take unpaid leave, keep working, or give up work altogether – harmed their longer-term career and financial prospects:

"I was in the process of training to be a barber at the time... It just got to the point where I couldn't do it anymore. I had to say, 'Look, I'm going to have to put this on hold because I can't do it. I've got all this stress from NICU. I've got all this stress with everything else. I just can't do it.'" - **interviewee who was 16 when his baby was born**

"I had to leave my job at that point because I couldn't do the work that I was doing with him being in hospital, so I just resigned completely from working." - **interviewee who was 22 when his baby was born**

Overall, 64 per cent of parents who responded to the survey reported that their family finances became either slightly or significantly worse due to their baby's admission to neonatal care.

Young people who lived with family were less likely to report a worsening of their finances compared to those living with their partner or who living alone (59 per cent vs. 69 per cent). This suggests that, for respondents who were not financially independent, the additional financial impact may have been

felt more acutely by their wider family. Young parents who lived with their partner, or who lived alone, will have also had additional financial commitments such as rent or mortgage and other bills, which may also account for this difference.

Several participants in both the interviews and survey described accessing Universal Credit and struggling to afford the basics for themselves and their babies. Some young parents benefited from the former Neonatal Expenses Fund (now the Young Patients Family Fund), which is only available in Scotland. Others received hospital bursaries, but not all were able to access these.

"I was getting help through the Universal Credit which has saved my life, and the hospital we were staying in was quite far away from where we live so it wasn't our local one. They were giving us a weekly bursary of £50 which helped out immensely, so we'd do our food shopping with that, and it paid for our taxis to the shops. It's how we survived basically so that's a really good system they have in place." - **interviewee who was 21 when her baby was born**

"We had no transport. No clothes for me my partner or child, little money for food."  
- **survey respondent aged 22-24 when her baby was born**

In addition to the costs of taking unpaid time off work, there can be significant additional costs associated with a neonatal admission, particularly to cover parents' food and transport so that they can be with their babies on the unit:

"We did get in a bit of debt from it all as well because obviously we had to use the credit card for the hospital parking and everything because that was so much a day and you have no choice, you have to pay it. Also the eating there and everything... It's just a lot..... I think if you were to have a baby in normal circumstances, it's expensive anyway, let alone not being prepared and having to quickly go and buy a steriliser and all the bottles on a credit card because you haven't had your baby shower yet. It was like, *oh my God, how are we going to pay this off?*" - **interviewee who was 23 when her baby was born**

# Young families after the neonatal unit



**Parents who needed psychological support were often unable to access it.**

Most young parents we interviewed found the experience of having premature or sick babies profoundly traumatic. Many reported diagnoses of postnatal depression or post-traumatic stress disorder after their babies were discharged and were on psychiatric medication, such as antidepressants, to manage this. These serious, and sometimes disabling, consequences were attributed partly to the lack of support they received during and after their baby's admission. The same themes were echoed in the survey comments.

**"During the time... in hospital, my mental health and wellbeing was being ignored and not considered at all. Due to not having support, I now suffer from postnatal depression and suspected PTSD." - survey respondent aged 19-21 when her baby was born**

The involvement group emphasised that they did not fully realise the impact of the trauma until their babies were six months to a year old. They spent the time on the neonatal unit and post-discharge in 'survival mode', just getting through it, but when the dust had settled, their mental health deteriorated. One member experienced a rapid onset of symptoms, including hallucinations, seven months post-discharge, and these were identified as being rooted in her time on the neonatal unit. However, she was not directed to perinatal mental health care but, instead, to a youth mental health service, who were not equipped to meet her needs. Other mothers in the group reported similar experiences; one felt that she was only signposted to the right support by coincidence because her GP was also the parent of a baby who had Hypoxic-Ischemic Encephalopathy (HIE). One interviewee was referred to a perinatal mental health service but did not receive appropriate support for her trauma:

**"They basically just said, 'You can either have medication or CBT therapy,' but my mum was like, 'She needs something now. She's got a young baby to look after and it's not going to end well if she doesn't have help now.' So, we went down the medication route and they did say, 'We're here if you need us for a year,' but I never actually heard from them, checking up on me and stuff... I feel like they just gave me the medication and sent me on my way." - interviewee who was 23 when her baby was born**

These experiences of inadequate care resulted in young parents being left to struggle alone with the impact of their trauma in the early years of parenthood. Subsequently, they were passionate about improving support for other young parents, as well as parents more generally who had experienced neonatal care or a perinatal mental health issue.

**"When I saw the opportunity come up to speak to you guys, I just thought... *if I can, in any way, help any other families that are going through the same thing.* Once it happens to you, it always stays with you. You always have a slightly different way of looking at things... and it's affected your life, so any help you guys need, or anything you want me to get involved with, I'm more than happy to do that." - interviewee who was 21 when her twins were born**



## Post-traumatic growth

Young parents also described significant positive changes in their own outlook or relationships as a direct result of their time on the neonatal unit:

**“I feel we’re a lot closer. We’re working together a lot more and... I feel more mature.” - interviewee who was 24 when his baby was born**

**“To be honest, having kids is scary, having a premature baby in a COVID hospital is even scarier, and then you come home and she’s a difficult baby. It’s just been really not what we expected, but at the same time we’ve really learnt to cope and adapt.” - interviewee who was 24 when his baby was born**

This is indicative of post-traumatic growth, a concept used to describe how adversity can be a springboard to higher levels of functioning and psychological wellbeing.<sup>xix</sup> This does not minimise the impact of trauma and suffering, or to justify it as acceptable. Rather, it is a testament to human resilience that, as someone recovers and rebuilds after a traumatic experience, they can also learn new skills and information about themselves and the world:

**“Emotionally, I think, now there’s been time to reflect on it, I think it made us all a bit stronger, but I just wish it hadn’t had to make us stronger in that way.” - 24 year old interviewee who has had three babies in neonatal care**

**“In spite of everything...that happened, we became better people, to be honest. We appreciate life more than anything and just being supportive to other people... just being more... non-judgemental, more kind to anyone...” - interviewee who was 24 when her twins were born**

For some, the neonatal admission constituted a turning point that has changed the course of their lives:

**“I actually think I would quite like to go down the career path of working with premature and sick babies. It really opened my eyes... I always wanted to work with families and children, but how much help we received in the NICU and stuff is definitely something I would like to look into as a career option.” - interviewee who was 21 when her twins were born**

**“It’s been of a hell of a journey... I’ve had to grow up so much, but it’s paid off because we’re now living at my mum and dad’s at the minute. We’re saving to get a mortgage. I’ve got a job now, as a barber... I’ve got my driving test tomorrow actually, and we... are actually getting somewhere.” - interviewee who was 16 when his baby was born**

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<sup>xix</sup>Joseph, S. (2012) What doesn't kill us... The Psychologist, 11(25): 816-19.

# Conclusion and recommendations

Having a baby born premature or sick can turn your world upside down. It touches every aspect of your life, including wider family relationships, work, and finances. Many parents feel that their hopes and expectations for pregnancy and birth have been destroyed.

While the vast majority of neonatal units work to improve the standard of family-centred care they provide – including through embedding the Bliss Baby Charter – limited resources and varying practices cause families to have vastly different experiences depending on where, and by whom, their baby is looked after.

For the young parents who shared their experiences with us, these recognisable impacts of neonatal care were intensified. Young parents tend to be more reliant on their own parents for emotional, practical and financial support, less confident in advocating for themselves and their babies, and under pressure to meet expectations around work or education with less access to the usual statutory support. These parents are often less prepared for the possibility that their baby may be born premature or sick – and they are less able to access appropriate support for their mental health and well-being when they need it most. Importantly, their experiences were not homogenous. There are significant differences between those aged under 21 and 22-24, particularly in terms of living arrangements and confidence when engaging with health professionals.

## 1. Bliss

This project has been an opportunity to understand how Bliss can better meet the needs of younger parents. We will:

- Co-produce new, tailored information and support packages for young parents, with young parents, and review how we market our existing resources so they are easily accessible.
- Review how to utilise the Bliss Baby Charter to support young parents' experience of neonatal care, and to ensure that assessments are asking for sufficient details in areas which affect young parents significantly, such as wider-family visiting.
- Review how best to engage and support young parents to be involved in shaping our work, and to ensure that they are more visible in our work and across our platforms.
- Ensure the experiences of young parents are embedded within our strategy, as part of a wider commitment to equity, diversity and inclusion.
- Review our approach to developing policy positions and work with young parents, and in consultation with other expert organisations, to campaign for policy changes to improve the neonatal experience for young parent families.

## 2. Neonatal service providers

There is an opportunity for NHS Trusts and Health Boards to facilitate improved support for young parent families with babies in neonatal care:

- Consult with young parents when producing or updating national, regional or Trust specific clinical guidance to ensure it meets their needs.
- Ensure neonatal healthcare professionals working with young parents' access training to tackle discrimination and unconscious bias. Neonatal Networks should consider developing a network-wide 'Young Parents' Pathway' to drive consistency. This should set out an approach to managing visiting policies in order to facilitate the presence of grandparents or other key support people when parents are young and/or single.
- Neonatal networks, maternity networks and LMSs (where applicable) should identify how best to ensure continuation of care for inpatient mothers with babies in neonatal care, while ensuring

inpatient mothers are supported to be with their baby as much as they wish, and are able, to be. Consideration should be given to training, and to the development of policies and procedures for caring for this specific cohort of women.

- The Maternal Mental Health Services (England) must ensure their services are inclusive of parents with a neonatal experience, and must ensure that there are clear clinical pathways for parents to access trauma-informed support.
- National NHS services and Governments should ensure all parents have access to psychological support in line with national standards.

### 3. UK Governments

Our report highlights several policies which are inadequate for the needs of young parent families. UK Governments must:

- Ensure the forthcoming Employment Bill makes provisions to ensure Neonatal Leave and Pay is accessible to all parents whose baby or babies require neonatal care.
- Include within the forthcoming Employment Bill an extension of Maternity Allowance to fathers and partners who are ineligible for paternity leave and pay, or other statutory support.
- Review guidance for supporting pregnant pupils and school-age parents with specific recommendations on how to support school-age parents if their baby requires neonatal care.

**“It’s been of a hell of a journey... I’ve had to grow up so much, but it’s paid off because we’re now living at my mum and dad’s at the minute. We’re saving to get a mortgage. I’ve got a job now, as a barber... I’ve got my driving test tomorrow actually, and we... are actually getting somewhere.” - Father who was 16 when his baby was born**

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