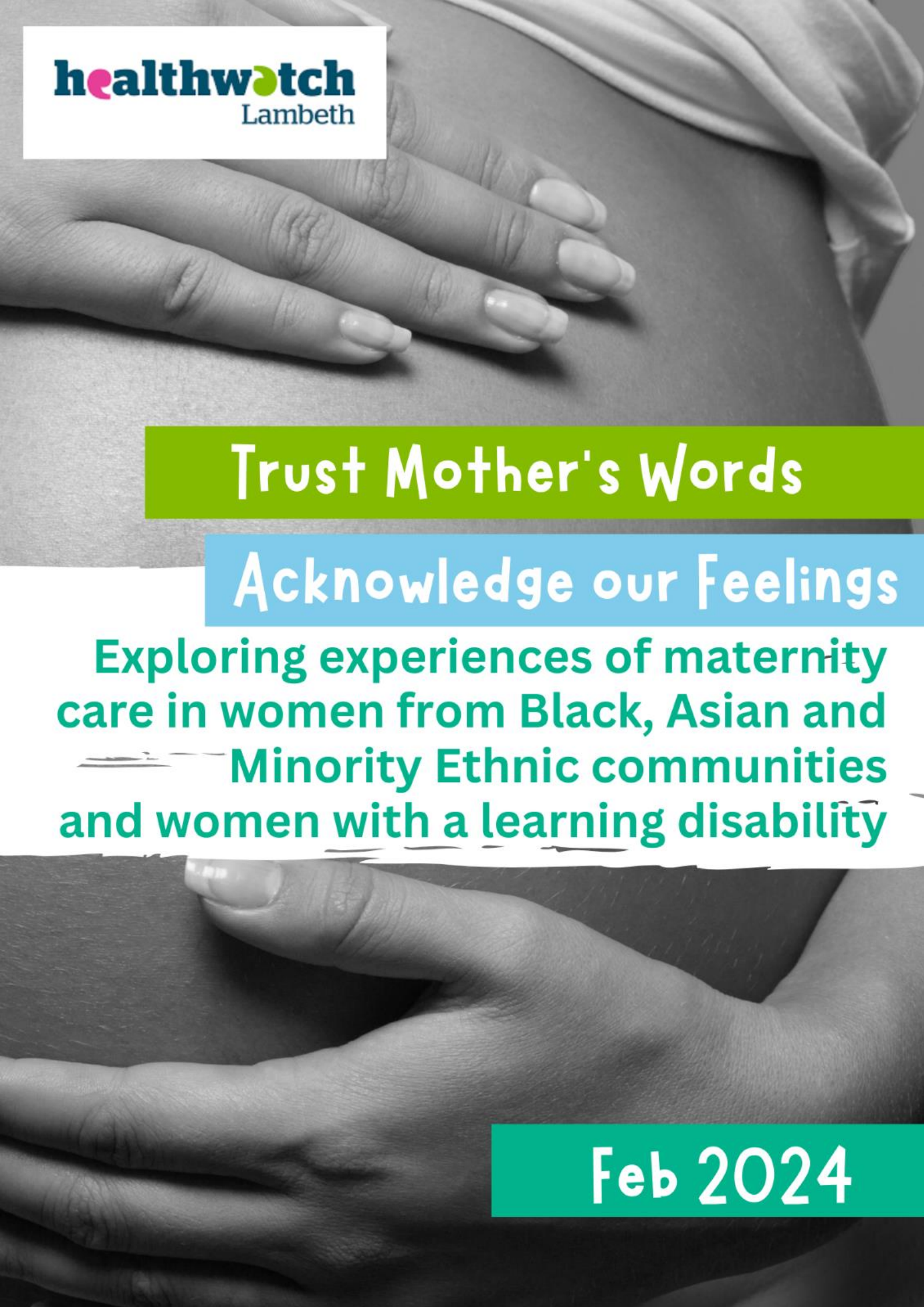

healthwatch Lambeth

Trust Mother's Words

Acknowledge our Feelings

Exploring experiences of maternity care in women from Black, Asian and Minority Ethnic communities and women with a learning disability

Feb 2024

Contents

About Healthwatch Lambeth

The Health and Social Care Act 2012 says that each Local Authority must arrange for an independent organisation called Healthwatch to champion the voices and experiences of the public in health and social care to promote better services for all.

At Healthwatch Lambeth we:

- Provide information about local health and social care services.
- Help people to find the health and care services they need.
- Get people involved in how these services are monitored, commissioned, and provided.
- Make known the views of local people about their needs and experiences of health and care services, to influence how services are commissioned, provided and scrutinised.
- Report on and recommend how services could or should be improved.
- Make the views and experiences of local people known to Healthwatch England, the national champion of people's voices.
- Make recommendations to Healthwatch England about advising the Care Quality Commission on areas of concern (or go directly to the CQC).
- Are a member of the Lambeth Health and Wellbeing Board.

Acknowledgements

We would like to thank ‘The Motherhood Group’, ‘Mummy’s Day Out’, ‘The Indoamerican Refugee and Migrant Organisation’, ‘Home-Start Lambeth’ and, the ‘Disability Advice Service Lambeth’ who partnered with us to deliver the project. Thanks also to the Chaplain of a local hospital trust who promoted the project for us. Most importantly, we would like to thank all the women who gave up their time to share their stories in person or through written feedback. Thank you also to SEL LMNS for their support of this work.

Executive summary

In January 2023, Healthwatch Lambeth was commissioned by South East London Local Maternity and Neonatal Services (SEL LMNS) to talk to pregnant/ newly birthed women/birthing people about their experiences of using maternity services. The aim is to use the insight of seldom-asked communities to develop and improve maternity services.

A total of 55 pregnant/newly birthed women/birthing people shared their experiences of maternity care through focus groups hosted and facilitated by local partner organisations, through individual interviews with Healthwatch Lambeth staff, and written feedback. Women from Black, Asian and minority ethnic groups, refugees, migrants, and women with a learning disability shared their stories.

Key findings

Our findings showed that women had variable experiences of the maternity care they received throughout the perinatal journey. However, many women described negative experiences.

- Women spoke highly of health professionals who showed sensitivity, listened to them and were responsive to individual needs and circumstances.
- However, for some women, a lack of person-centred care and at times a near-focus on structural aspects of care combined with limited relationship building and trust with care professionals left many women feeling anxious and often processed.
- We heard that not being trusted and feeling ignored by healthcare professionals in relation to early pregnancy complications or when experiencing pain during labour and birth left many women feeling alone, uncared for and disrespected.
- The provision of information, good communication, positive staff attitudes and continuity of care was key to a positive experience of care. However, many women's stories highlighted that this was often lacking and resulted in a loss of autonomy and control. This meant that many women felt unable to express their care preferences and often felt conflicted and 'pressured' or 'funnelled' into decisions about their care. Lack of continuity also meant women were unable to build an ongoing relationship with a health professional.
- Some women felt judged when faced with what they perceived to be differential or lacking care based on factors including their age, ethnicity, citizenship, and accent. They gave specific examples including stories about gestational diabetes screening, pain management during labour and when needing physical and practical support on the postnatal ward.

- Care after birth was frequently described as poor. In hospital, women's requests for physical and practical support were often not met. This left women themselves feeling abandoned and helpless, particularly after traumatic births. Some women witnessed unprofessional interactions between staff on the ward.

- Inconsistent postnatal care after discharge and what was perceived to be an exclusive focus on the wellbeing of the baby also resulted in many women feeling that their physical and emotional needs were not met or acted on in a timely fashion.

There were particular issues raised by individual groups/communities of women which also contributed to their perceptions of maternity care.

- Some women from the black community, described cultural practices around the care of a newborn that they felt did not always align with 'normative advice'. The often felt conflicted and wary of discussing practices with healthcare professionals.

- Spanish and Portuguese-speaking women frequently described language and communication barriers and variable access to interpreting services. Dissonance in relation to care expectations and perceived lack of awareness of health professionals in relation to rights to NHS care also contributed to perceptions of poor care.

- South Asian women shared very traumatic experiences particularly around the time of birth which they often perceived as negligent and resulting in enduring psychological distress.

- For women with a learning disability, the added involvement of social services contributed to poor maternity experiences. Being under the 'watchful eye' of health and social care professionals whilst in hospital after birth led to a loss of autonomy and control and feelings of being judged. The involvement of social services also led to delays in discharge.

Recommendations

We would like to acknowledge that maternity care staff work hard to provide maternity care to all women but in light of our findings there is room for improvement. Key recommendations are summarised below with more detail provided in Appendix 2 in the report. We would like to see the following:

- Provision of personalised care conversations and training around this with a strong emphasis on active listening, and efforts to treat women with respect and dignity.

- Provision of clear and accessible information to enable women to feel involved, make choices, understand and navigate the maternity system at all stages of the perinatal journey.

- Improved provision and promotion of interpreting services for women who need it.

- Efforts to improve continuity of care through a named midwife (or a small team) providing opportunities for women to build trusting and supportive relationships with health professionals.
- Training to challenge negative staff attitudes, including equality, diversity and inclusion, the role of unconscious bias and what constitutes non-stigmatising care. This should be followed by regular reflective practice – focusing on how staff interactions and biases can impact women's experiences of care focusing on professionalism at all times.
- Addressing staff shortages to improve quality of care during labour and birth and postnatally in the hospital ward so that women are not left feeling isolated and abandoned.
- Postnatally, women are asked about their own health and wellbeing and that of their baby in line with NICE guidance on postnatal care and are referred to physical and emotional support where needed.
- A systematic approach to reviewing service provision and making ongoing quality improvements including providing opportunities for women to feedback about their care and case reviews when women report traumatic experiences or perceive care to be negligent.
- Maternity services to leverage partnerships with voluntary and community organisations supporting diverse communities to enhance service provision. This would help to raise staff awareness of the rights of migrants to NHS care, and of cultural practices in relation to pregnancy, birth and the care of the newborn. This would also enable services to signpost women to available community support.
- Joint working with social services to ensure maternity care for women with a learning disability is a supportive process and to minimise delays in discharge from the hospital.

Background

The transition to motherhood is for many women a major event that can be both joyful and bring about significant challenges. The care a woman receives during pregnancy, whilst giving birth and after birth can have a positive and negative effect on her experience of maternity care and her health and wellbeing.[1]

Whilst most women report positive experiences of their maternity care, there is evidence to suggest that maternity services are still struggling to provide care that meets the needs of women from specific groups. Existing evidence suggests that women from Black, Asian and ethnic minority groups, women with disabilities and women from poorer backgrounds are particularly vulnerable to poor maternal and infant health outcomes including death from pregnancy, premature birth, stillbirth and neonatal deaths.[2-4]

Policy initiatives over the past decade have aimed to improve the quality of NHS maternity care ensuring services are kind, compassionate, supportive and adopt a woman-centred approach.[5] However, evidence of their impact in addressing inequalities is poor.[6]

Research has also shown that women from Black, Asian and minority ethnic communities, women from poorer backgrounds[7-9] and those with physical and learning disabilities[10-11] are less likely to report positive experiences of maternity care including not feeling that they are treated respectfully and not feeling involved in decisions about their care. Women from Black, Asian and minority ethnic groups also cite poor communication, lack of respect for cultural needs and experiences of discrimination.[7, 9]

The local context

Southeast London (SEL) has a significantly higher percentage of women living in the most deprived areas booking in for maternity care. In line with national audits, the maternity population of SEL has a higher chance of adverse maternity and neonatal outcomes including rates of preterm birth, stillbirth, and neonatal and maternal mortality. More specifically, Black women have a higher rate of stillbirth compared to other ethnic groups and in Lambeth this group of women have a higher stillbirth rate compared to the rest of SEL.[12]

Project scope and aims

In January 2023, Healthwatch Lambeth was commissioned by South East London Local Maternity and Neonatal Services (SEL LMNS) to talk to pregnant/ newly birthed participants/birthing people from seldom asked groups about their experiences of using maternity services. The findings would help to inform service development and improvement across South East London with the ultimate aim of ensuring maternal healthcare services are inclusive and supportive to all who require it.

The specific project aims were to:

1) To explore pregnant women and newly birth participants/birthing people's experiences of giving birth in South East London with a specific focus on:
    - Pregnant/newly birthed migrant participants/birthing people including asylum seekers.
    - Pregnant/newly birthed participants/birthing people from Black, Asian, and Ethnic Minority groups
    - Pregnant/newly birthed participants/birthing people with a disability
    - Pregnant/newly birthed participants/birthing people living in the most deprived areas of Lambeth.
2) Reach out to seldom-asked maternity communities in Lambeth by developing partnerships with local voluntary and community sector organisations who work closely with the communities of interest and, where possible, to co-deliver the engagement activities.

Methodology

Recruiting participants

Healthwatch Lambeth worked on the project actively engaging maternity service users between May and October 2023. This involved establishing new partnerships with voluntary and community sector organisations (VCSOs) in the borough who worked closely with the communities of interest.

Participating organisations included:

- The Motherhood Group and Mummy's Day Out – both user-led groups supporting pregnant and newly birthed participants/birthing people and run by women who had experiences using maternity services in South East London.
- The Indoamerican Refugee and Migrant Organisation (IRMO) – supporting people from Latin America and Spanish and Portuguese speakers.
- Disability Advice Service Lambeth (DASL) – working closely with people with disabilities – physical and learning.
- Home-Start Lambeth – supporting families with young children under five.

These organisations were responsible for recruiting between 10 and 12 pregnant/newly birthed participants/birthing people to participate in the project. They were also responsible for hosting and facilitating focus group discussions and providing interpreting where needed.

We also obtained written feedback from women of South Asian background.

Interviews and settings

A total of seven focus groups and four individual interviews were conducted. Individual interviews with women with a learning disability were conducted by Healthwatch Lambeth staff and were also attended by a support worker who had briefed the women prior to the interviews and was on hand to provide a reassuring presence and explanation of questions where needed.

Focus group discussions and interviews took place in safe spaces in venues that women were familiar with or comfortable with. Refreshments and shopping vouchers or goody bags were also given to women who took part in focus groups and individual interviews as a thank you for their time.

Interview topics

A flexible topic guide was used. VCSOs who hosted, facilitated, and ran focus groups adapted questions to meet the needs of those participating in ways that would

encourage discussion. Women were asked to share their stories and comment on the following:

- Overall experiences of maternity services including interactions with health professionals and involvement of partners and/or carers.
- What was good about their maternity care/what worked well.
- What could be improved.

Profile of women

To be eligible to take part in the project, women had to:

- Have given birth within the last two years.
- Have to have used South East London maternity services
- Preferably be Lambeth residents.

A total of 55 pregnant/newly birthed participants/birthing people shared their experiences of using maternity services in South East London. Women who provided information gave birth in South East London Hospital Trusts.

Demographic information for this project was incomplete as not all women provided this information. Of the women who provided this data approximately 30% self-identified as Black African, Black Caribbean or Black mixed origin, 20% identified as Latin American and 15% were of South Asian origin (Nepalese or Indian).

Key findings

In this section, common themes emerging from interviews across all groups and that cut across the whole perinatal journey are highlighted to avoid duplication. Where specific references are made to different stages of care i.e., antenatal care and care during labour and birth this is cited in the commentary. The only exception being experiences of postnatal care which has its own section.

The importance of person-centred care

Having a health professional who provided person-centred care tailored to individual needs and delivered with sensitivity was seen as contributing to good maternity care and was valued by participants. Some described midwives/health professionals as 'lovely', 'very nice' or 'really good' and gave examples of positive care at different stages of the perinatal journey which made them feel valued and cared about.

"They [midwives] have been so nice and so lovely…I was scared to have normal injections and taking bloods, they offered me the baby one to take my blood. It's just little things like that."

"Overall, my experience was great. The midwife listened, and one thing was really helpful when she gave me lavender when I was having contractions. She could see that I was struggling so she said, 'Let's try this little thing,' and I am grateful for that."

Person-centred care was also characterised by the presence of empathy, good communication, feeling listened to and being given time to talk.

"I had a final appointment at the hospital with a consultant who discharged me after reviewing all the scans and telling me I was no longer at risk (as my glucose had been high). She was wonderful, looking at all my scans, listening to me, explaining everything and encouraging me, even acknowledging that I am a Black woman, saying that I should focus on taking Vitamin D, very important to Black people. I left the appointment feeling very happy and empowered."

Conversely, we heard many stories which illustrated an absence of kind, sensitive and person-centred care which left women feeling anxious and processed 'on a conveyor belt'.

“I feel that we are treated as a number. I lived 20 years in Spain and there is a huge difference in the treatment. Here it's like you're just a number, you don't matter. If it hurts, you put up with it, who told you to get pregnant? It's all very cold...They need to have a sensitivity course.”

”The sensitivity is not there. It’s kind of like a conveyor belt, they just want to get you out!”

One woman described how the focus on structural and procedural aspects of care meant that information about a potential miscarriage was communicated to her in an unfeeling and insensitive manner, exacerbating her existing anxiety with long-lasting effects on her wellbeing.

“I was alone in the room, being in a terrible mental state. The doctor did not even care about my physical or mental status. After examination, the Doctor said ‘this is 50% miscarriage and needs to be confirmed by an ultrasound scan. He insensitively revealed the information without empathy or not even sympathy. He also told me there was no slot for a scan and to wait a few days to get a scan done, I was bleeding continuously and couldn’t imagine waiting days for a scan. I couldn’t control my tears. I was hopeless. The mental trauma from this experience was very deep. It took months to recover. Our healthcare system is like a robot now, randomly performing the structured tasks.’”

The need to be trusted not ignored or dismissed

A key feature of women’s experiences was a perceived reluctance on the part of health professionals to trust or listen to them and take them seriously. In the worst cases, requests for help and support for pregnancy sickness, bleeding during early pregnancy, physical changes during labour and birthing and requests for pain relief or use of alternative methods to manage pain were often dismissed, ignored, or met with disdain.

“As my contractions were increasing, they said they couldn’t give me any strong painkillers as there were no doctors to prescribe it. At 3am I felt like my waters had broken and I was having unusual colour discharge. I approached one of the midwives, but she didn’t give much attention to it. The foetal heart rate was dropping, and they suddenly called for the emergency team. Thinking about my experience, if I was given effective pain management and if I was heard properly when I reported a change, things could have been more effectively managed.”

“I was utilising the hypnobirthing approach. The midwife made it quite clear that she was anti that and she was like ‘Don’t you start with that hypno-rubbish.’”

“I had a birth plan written by the consultant midwife, they [hospital staff] didn’t even look at it. I’m still having to ask nicely for the epidural that I was promised.”

One woman felt that dismissive care by the early assessment team alongside receiving conflicting information about the length of labour resulted in an unplanned home birth.

"I contacted the early assessment unit at {hospital name} and spoke to a very unhelpful and dismissive lady. She didn't pay attention to my medical history, just saying you need to labour for this amount of time and then you call us back. She didn't ask me if it was my first or second child. I then learned that her advice was wrong because, with your second child, you are meant to labour for 45 minutes whereas she told me 2-3 hours. That's why I ended up having an unplanned home birth because my water broke and was in so much pain that there's no way I could have moved."

Feeling ignored and dismissed left women feeling uncared for and isolated at a time when they were vulnerable and needed support. Women's stories also imply that they were not seen as competent to make judgments about their needs or about their bodies. In this context, they frequently described the need to be heard, trusted, and believed and used expressions like 'trust the mother, she knows her body', 'trust mother's words' and 'acknowledge my feelings'. This was seen as paramount to good maternity care.

"I think trusting and believing mothers words is important. I was alone in the room. My experience of being in pain and literally being ignored so for me being listened to and trusting what mothers say is what good care should be."

Information, choice, and control

This theme describes the need to feel informed, given a choice and feel in control of decisions about maternity care and the care of the baby. Good communication and information are often described as key to ensuring women feel involved and empowered.

"She [the midwife] broke down the different options I had…I left feeling so empowered, I didn't know I had all these choices and options."

However, we heard several stories that illustrated that this was often lacking, leaving women feeling powerless, frightened, conflicted, and at times unable to challenge. Situations included the administering of medications and carrying out medical tests or procedures without providing relevant information or explanation. Some women also described staff as 'insisting on their views and some described feeling 'funnelled', 'forced', or 'pressurised' into situations or decisions.

"…Because I was older, I saw an obstetrician sporadically. At every appointment they were trying to make me have a C-section…it got progressively more forceful …and then, in the end, when I was actually in labour in [hospital name], an obstetrician came round and said if you don't have a C-section, you could risk your baby being brain damaged, and it was horrible. I was on my own, in tears."

"The injection they gave me, I remember I said, 'What is this for?' They told me it's because I needed it. And I didn't know, I didn't have a lot of information and I was alone. And when they told me 'You can choose not to get it,' then I had a feeling that... What should I do? Should I get this injection or not? I accepted it but I didn't know."

Several women when reflecting back on their experiences described how they wished they had spoken up for themselves and felt empowered to explore other options.

"I have fibroids and that fashioned my experience. It was almost as if I had a C-section preassigned. When you are less informed about the choices you have, you are funnelled into the decisions that the professionals tell you. But had I spoken up and understood what other choices were available I think I may have probably waited a bit more and explored the possibility of natural birth and seen a specialist consultant that deals with natural deliveries after a C-section."

Staff attitudes and interactions

Feeling judged and/or blamed was a key feature of many participants' perceptions of their maternity care, particularly in relation to race/ethnicity, citizenship and age.

Some women from the Black community described situations where it was implied that they should be able to manage their pain because they were 'Black' and therefore perceived as being able to tolerate pain.

"Your background can interfere with how they treat you and they didn't believe me about that I was contracting. As an institution they probably have the idea that you are Black, so you are strong."

These women also described feeling 'blamed' or 'labelled' when being offered gestational diabetes screening during their antenatal care.

"One thing I am really annoyed about is I had to have a gestational diabetes screening test purely because of my race. I am not at risk for any other factors, and it just seems that they think that by being Black or Asian, it causes gestational diabetes, but it's more like being Black or Asian puts you at risk because of other factors about society and it feels like they are almost blaming me for it."

Migrant women linked poor care with their nationality, citizen status and accent.

"I could hear from afar, the nurse going and speaking to others who had English accents and helping them. A question I ask even today just by looking back at those memories: would this happen, if the mum was British? Would they not raise a complaint? Is it because we do not have citizenship, but they do? We are a minority, but they are not!"

"My mother had to call the nurse several times to come and change my pee bag. My mother was indignant, she saw that the nurse was talking to other nurses, and she didn't come. I realised that the treatment of British people is different, it seems like we don't pay taxes. And taxes are very high for everyone. I don't understand why they make differences. It's very frustrating."

During discussions in one focus group, women highlighted the need for more unconscious bias training, but in doing so they were also concerned that training might not translate to changes in everyday interactions.

Shared experience – 'someone who gets you'

Women also expressed the need to be cared for by maternity care professionals with shared experiences of giving birth and whom they felt they could relate to and trust. In this context, women described needing HCPs who 'get you' and understood their struggles and difficulties.

"I found it initially quite difficult to breastfeed. My midwife properly deterred me from giving her a bottle. Like making me feel that the worst thing I could do was give her a bottle. And through that whole experience, I was stressed. I was, like, sometimes crying. And then when they discharged me finally. I said to her 'Do you have any kids?' And she said 'No.' And I felt you don't know what I am going through. You are just doing textbook."

"You are not asking for someone to come in and be your mum, but they get you, the struggles and that's my opinion. Do you get the struggles, do you really understand what I am going through right now?"

"I went from one [health visitor] who was very empathetic to another who I did not like their treatment. And especially when I asked her how many children she had, zero. None of them had children. It made me angry because they gave me advice but not their own experience."

Continuity of care

Another theme that emerged from feedback relates to 'continuity of care' i.e., whether women had care from the same maternity care professional or were seen by different people. The importance of this aspect of care has been highlighted in previous maternity care research and is a priority area in maternity policy and guidance. Where continuity existed, it was valued by women because it enabled them to have a trusting

relationship with an individual HCP making it easier to talk about any worries or concerns and helping them feel more connected and positive about their care.

"This time round my care has been much better. I've got one midwife. I know her. I haven't seen anyone else. She's been my one midwife. That's been really good cos I feel like I can connect with her, I can talk to her. My experience is she's been able to refer me to different departments better because she knows what's going on."

For women with a learning disability who may be experiencing additional challenges and vulnerabilities, continuity of care was of paramount importance. Familiarity, building trust and maintaining confidentiality were seen as key features of good care.

"Having the same midwife … For me it's important to have the same person…I don't like to meet someone else and explaining things all over again, so I like that consistency, having the same person."

Women who saw numerous maternity care professionals described their frustration at having to re-tell their stories and update them on their care needs and preferences.

There are many different midwives, and you have to repeat everything to every single one of them. I had 5 midwives. I had to tell them what was going to happen. It is different when you only have one and she knows everything that is happening to you. You don't have to repeat yourself constantly."

Care on the postnatal ward

Physical care and practical support

In their discussions about care after birth and their stay on the postnatal ward, women often recalled how their pain and aftereffects of birth, including caesarean or uterine tear, made it difficult for them to move around and care for their babies. In the worst cases, women felt isolated, abandoned, and helpless in hospital. Requests for practical help and support with attending to wounds, getting up, lifting babies, feeding, using the bathroom and attention to basic hygiene were commonly ignored. There was often considerable delay before anyone came leaving women feeling alone, in tears and at times neglected.

"Because of a wound infection, I stayed in hospital for 12 days. No one came to me or to see my child and they did not check my bleeding or did not ask me whether I know how to feed my baby. I heard staff assessing and doing breastfeeding assistance to mothers in the same bay. But no one came to me. I was in lots of pain and asked for help to get out of bed and the response was 'It is normal to have pain and you need to do it yourself.' I told her [the nurse] that I have a wound infection, but she did not bother. There were instances where I left my baby near my bedside and went to the toilet. I heard him crying until I came back. It

might sound silly but for me as a first-time mother leaving my child alone crying was miserable. Every day I used to cry, and they did not give me any support."

Food and nutrition

The food provided in the hospital was also subject to criticism. Some women described the food as inadequate, lacking in nutrition and inappropriate for dietary requirements.

"I was a gestational diabetic and one of the things I found with the services was whenever I was admitted to the hospital it was very hard to eat. So, the food that they provided, it doesn't take into consideration that I'm a gestational diabetic."

"The three days I was in hospital they gave me chips and sandwiches 2 times a day. I think a person who has a caesarean section has to have a soft diet."

Professionalism of staff

Several women talked of witnessing poor professional standards. For example, shouting and arguments between staff. This was distressing at a time when women needed rest and/or were recovering from sometimes very traumatic births.

"After giving birth, there were two midwives on the ward arguing between themselves and there were about 5 other women on the ward just given birth and you just don't want that negative energy around you. That was horrible for me."

Care after discharge – physical and emotional wellbeing

Some women had positive experiences of care after discharge, valuing maternity professionals taking an interest in their health, listening, and explaining where appropriate.

"She [the midwife] checked baby, checked my stomach and listened to what I was saying so not dismissive. I felt empowered as she explained things to me."

However, care from maternity care professionals in the period following discharge was also subject to criticism. For example, some women described care as being focused on the wellbeing of the baby rather than the mother with health problems being overlooked or not sufficiently addressed.

"I thought they were meant to check my baby and have a physical check for me, but they only checked the baby and asked me questions. I kept saying that something was not right later because of pain in my belly button. I had to be referred to the hospital and the gastroenterologist confirmed I had a hernia and diastasis recti. I feel I was the one who had to follow this up as I was not given support."

Some women described experiencing psychological distress in the days after discharge. Staff were often seen as 'bad' at recognising indicators of poor mental health leaving women to struggle alone. Those who were referred for support were faced with long waits and inconsistent follow up which may have exacerbated their distress. The situation was worse for women who had little or no social support from family or friends.

"I have no family here. My husband is here but his paternity leave is only 2 weeks. I was alone with a caesarean section, with a newborn baby and a 3-year-old child. It was winter, I could not even move. The child was crying all the time. I wanted to ask for help. I wrote an email to the NHS for mental health support because I was coming in and I was sinking. The loneliness, the darkness, everything weighs on you. I asked for help, I phoned, they referred me elsewhere, but they didn't call me back. One day, I had an anxiety attack and I contacted them again. In the end, they referred me, but the waiting list was very long."

Sometimes the stigma attached to mental health made it harder for some women to openly share their anxieties with maternity care professionals for fear of being labelled.

"I had a little bit of a taboo because I didn't want to be labelled or have some label. I just needed someone to tell, someone to talk to. I was eventually on the waiting list to chat with a counsellor, but it took six months."

"I feel like when I gave birth to my son, I feel like I lied a lot to the health visitor about how I was feeling, things like mental health—I said I was fine, but I was struggling a lot."

The value of support networks

Women also talked about the value of support networks in supporting them through their perinatal journey. Several women mentioned their mothers as playing a key role in advocating for them and asking questions.

"After the birth, I had my mother at home with me when the doctors came. As a first-time mother, did not know what to worry about, what to ask. My mother asked everything. The doctor was very good. The midwife that I had the last month helped me a lot and had a lot of connection with my mother. She talked to her, answered everything. I can't complain about that part. That was very good."

"My mum was coaching, encouraging, as women do, naturally. My family were key in supporting me and played a key role in my recovery. Knowing that they were there, made the difference to me."

Women also described the desire to be linked by maternity care professionals to networks within the community particularly where there might be opportunities for wider support from other mothers or from people who spoke the same language. This was seen as particularly key for women who did not have their wider families around.

"I was fortunate that I told them I needed someone, and they put me with a group called Olive in Lambeth where I live, in Streatham. They would put you in these groups if you wanted to, for example in a certain language."

Information and support needs

Women talked a lot about their information gaps and raised questions that encompassed the entire perinatal journey. Whilst some women shared tips and suggestions as part of the focus group discussions women highlighted the need for professionals to provide information and support around the pregnancy and preparation for birth, caring for and feeding a newborn, health and identity after birth and structural and organisational aspects of care. (More detail about women's information needs is provided in Table 1 in Appendix 1)

Findings from specific communities or groups

Each of the groups shared experiences that were less common across all women who participated. These are highlighted below.

Women from the Black Community

The role of advice and culture

Some women noted how advice from their families and certain cultural practices did not always align with 'normative' health advice, particularly around feeding and the care of a newborn. This caused stress for some participants, leaving them feeling conflicted about going against familial or cultural norms or not feeling able to talk openly about their feelings with health professionals.

> "I was told by mum that on birth give water to your baby or they will be dehydrated but my nurse was telling me don't give water to your baby till they are six months. I didn't know what was right."

One woman described the Nigerian tradition of massaging a newborn. She felt unsure and anxious about safety but felt unable to discuss this with HCPs for fear of being judged or raising a safeguarding concern.

> "My son is Nigerian, and his grandma was stretching him, and I was like 'what is going on?' and I never spoke to my health visitor about that because I was thinking she might be like that's dangerous. I was anxious about it. I was thinking if I told them my baby is being stretched out, they might be like that's a safeguarding concern, so I felt I wasn't able to be completely honest with my health visitor."

Raising awareness amongst professionals either through training or through encouraging women to talk about mental health and cultural practices concerning newborns was seen by women as providing opportunities to open up conversations.

Refugees and migrants

Language and communication

Several Spanish and Portuguese speakers talked about difficulties with communication as English was not their first language. Not being able to express themselves left women feeling powerless, with some unaware of the opportunities for interpreters.

"I don't speak English and that's a barrier. You feel powerless to express everything you feel."

"Many people who have language barriers don't know they can ask for an interpreter."

The impact of expectations

Women in this group also compared maternity care they received in the UK with care received in their home countries. Antenatal care was seen as insufficient, particularly where women felt they needed more specialist care, for example when being diagnosed with preeclampsia (high blood pressure) and/or diabetes. Antenatal checks were also perceived as being less thorough where information about the development of the baby or good nutrition during pregnancy was perceived as lacking.

"They don't give you advice on nutrition vitamins or anything else. That does not happen in Spain and South America. There are medications approved by the World Health Organisation for women who have frequent vomiting syndrome but here they do not take into account."

Some women felt they were either discharged from the hospital too early or felt pressure to leave the hospital when they felt less physically able to for example, after experiencing complications or having a caesarean birth.

"Every day I was stressed because the nurses would come and tell me I had to go home. They asked me if I liked living there. I told them I couldn't move and only on the third day I could stand up. It was horrible…I despaired because I was questioned all the time why I was still there…In Spain, it is usually three days for natural delivery. You stay in the hospital for five or six days later you have a caesarean section."

Rights to NHS care

Women also expressed concerns about misinformation among maternity care professionals about migrant's rights to access NHS care. Language barriers made it difficult to challenge or correct this misinformation resulting in women feeling stressed and fearful.

"They make patients afraid because of their immigration status. I was referred to a centre, Gaya, because I had a high-risk pregnancy. There, they told me that I could not access the service because I was neither English nor European when I have permanent residency. I have permission to work and receive benefits. They said I was going to have to pay for my delivery in instalments. They did not have an interpreter. I understand English but I can't communicate sometimes. I knew they were wrong because I looked on the internet. I know that everyone has the right to access health care without fear."

Traumatic birth experiences and perceptions of negligent care

Several South Asian women described traumatic experiences during early pregnancy or at the time of birth. In this context, they judged their care to be poor and sometimes negligent. This resulted in enduring psychological distress.

"I lost about 1.5 litres of blood. One of the doctors explained to me the procedures and also said if the bleeding continues it could lead to death! I was not really processing the whole situation and I was traumatised. After discharge when I went through the medications given, I realised that one medication 'Enoxaparin' was not there during discharge, so we had to go back. That was another negligence. The whole experience was absolutely nerve-wracking, and I still panic thinking about another childbirth."

From written accounts of the care received it was unclear whether women followed up on their experiences through a formal complaints process or other available avenues.

Women with a learning disability

For women in this group, stories about their maternity care around what happened to them whilst in hospital after birth and in particular the involvement of social services.

Loss of autonomy and control

The involvement of social services in their care led women to feel a loss of control and autonomy. Being under the 'watchful eye' of health and social care professionals meant that women had little privacy and lost their freedom and independence.

"Social services got involved. I was in the side room. And then one of the nurses had to sit in the same room as me and watch me 24/7. And I felt really uncomfortable. I didn't really like the experience. Even though I was in the side room I did not have any privacy at all. I don't like when social services get involved. I feel so uncomfortable when someone is watching me. Even at night, someone is in the room as well."

"Where I had social care involved, I was not allowed to leave hospital with my child unless they say I can leave the hospital. So, I felt a bit frustrated as I had previous children before."

Feelings were exacerbated by delays in processing paperwork which resulted in long stays in hospital without adequate facilities for partners, family members or carers to stay and provide support where needed.

A recurrent theme in women's accounts was the stress of having their abilities as a mother assessed after birth. In this context, women felt judged and discriminated against despite having had children before.

"They said because of my disability I would not be able to cope. I think it is discrimination."

"Things could have been better if they had given me a chance. They shouldn't have taken my baby away into foster care. It was not as if it was my first child."

Conclusions

Our research explored the experiences of maternity care amongst Black, Asian and minority ethnic groups including refugees and migrants and included women with a learning disability. Women's accounts of their care indicate both positive but largely negative experiences of maternity care. Positive experiences were often the exception with some examples of person-centred care, good communication and women feeling involved in their care. Negative experiences included and are not limited to issues related to communication, staff attitudes, feelings of being judged, and physical and emotional needs not being addressed.

Health professionals working in maternity care play an important role in helping women cope with the challenges associated with becoming a mother and guiding them through the system with information and support. Good communication and the provision of accessible information is key. Training should help maternity professionals to understand the challenges that women face when using maternity services emphasising the need to listen, show kindness, give time and provide personalised care conversations. Of paramount importance is the need to challenge negative staff attitudes and judgements based on an individual's background to ensure that all women using services are treated equally and with respect.

Whilst policy initiatives over the past decade have aimed to improve the quality of NHS maternity care ensuring services are kind, compassionate, safe, and supportive and adopt a person-centred approach to meeting the individual needs of women and babies, our findings show that there are still gaps in implementing this vision. Our findings are also consistent with other research in the UK that has focused on the experiences of diverse ethnic communities and women with disabilities.

Strengths and limitations

The main strengths of this community engagement project are:

- Partnering with VCS organisations who work with and support women communities of interest who do not often take part in research.
- Enabling women with shared experience or group leads who already have the trust of their communities to host and facilitate the focus groups and
- Conducting focus groups and interviews in safe spaces where women could speak freely, openly, and authentically, share experiences and exchange information and tips to support each other during the perinatal journey.
- Providing easy read materials for women with a learning disability and briefing them in advance of interviews.
- Ensuring the presence of a reassuring and familiar support worker during interviews with women with a learning disability.

Limitations included:

- Not being able to get a talk to a larger number of women with a learning disability therefore whether their experiences are representative of a larger group of pregnant/newly birthed women/birthing people is not known.
- Anonymous written feedback provided by some participants did not allow us to follow up on some of the concerns raised in written accounts of their care in detail.

Next steps

In light of the feedback provided by women, Healthwatch Lambeth looks forward to collaborating with South East London Local Maternity and Neonatal Services and other relevant committees and boards to explore how best to implement the recommendations outlined in this report.

References

1. Redshaw M, et al . Women's experiences of maternity care in England: preliminary development of a standard measure. BMC Pregnancy and Childbirth 2019;19; 167. Accessed January 2023

2. Knight M et al. Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19. Maternal, Newborn and Infant Clinical Outcome Review Programme; 2021.

3. Knight M et al. A national population-based cohort study to investigate inequalities in maternal mortality in the United Kingdom, 2009-17. Paediatr Perinat Epidemiol. 2020;34(4):392–8.

4. Knight, M et al. (2020). MBRRACE-UK: Saving lives, improving Mothers' Care 2020: Lessons to inform maternity care from the UK and Ireland confidential enquiries in maternal death and morbidity 2016–18.

5. NHS England. National Maternity Review: Better Births – Improving Outcomes of Maternity Service in England. 2016

6. Puthussery S. Perinatal outcomes among migrant mothers in the United Kingdom: is it a matter of biology, behaviour, policy, social determinants or access to health care? Best Pract Res Clin Obstet Gynaecol. 2016; 32:39–49.

7. Khan Z. (2021) Ethnic health inequalities in the UK's maternity services: a systematic literature review. British Journal of Midwifery VOL. 29, NO. 2 |

8. McLeish J, and Redshaw M. Maternity experiences of mothers with multiple disadvantages in England: A qualitative study Women and Birth 32 (2019) 178–184

9. Thomson et al. Minoritised ethnic women's experiences of inequities and discrimination in maternity services in North-West England: a mixed-methods study. BMC Pregnancy and Childbirth (2022) 22:958

10. Lawler et al. Access to maternity services for women with a physical disability: a systematic review of the literature. Int J Childbirth 2013; 3 (4):203–17.

11. Redshaw M. et al. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. Redshaw et al. BMC Pregnancy and Childbirth 2013, 13:174

12. Lambeth Together Strategic Board (September 2022) Unpublished data on maternity

Appendices

Appendix 1 – Women's information and support needs identified during interviews

Table 1 – Information and support needs

Topic area	Information or support needed
Pregnancy and preparation for birth	Management of sickness in pregnancy Options for birth and planning Options around pain relief including non-medical pain relief options Access to in-person antenatal classes Access to mental health support and opportunities for debriefing after birth Access to scans
Caring for and feeding your baby	Practical breastfeeding support including demonstration of different positions and techniques Concerns about whether the baby is breathing when asleep Caring for a child with special needs Returning to work and leaving your baby in a nursery
Women's health	Sex after birth – will it be the same and how to improve it Coping with sleep deprivation Postnatal depression – will it happen, will it go away and how to access support if it happens Bonding with newborn – is it normal not to feel a connection with your baby and being prepared for this Opportunities for a coping skill course
Identity as a mother	Coming to terms with a new identity,

	Understanding how these impacts on relationships with friends and family How to sustain relationships and find time for oneself
Social support	Access to peer support groups in the community
Structural and organisational aspects of care	Hospital systems and processes and what will happen at each stage Number of antenatal appointments and approximate length and what to expect Care after birth and what to expect

Appendix 2 – Recommendations in more detail

We would like to acknowledge that maternity care staff work hard to provide maternity care to all women but in light of our findings there is room for improvement:

Person-centred care

- The provision of personalised care conversations tailored to individual needs and circumstances and training around this with strong emphasis on active listening, and efforts to treat women with respect and dignity.

Communication and information

- Provision of clear and accessible information to enable women to feel involved, make choices and navigate and understand the system at all stages of the perinatal journey. This would include information about:
    - Pain relief and birth options including options for birth where there are pre-existing clinical factors for example fibroids might impact those choices.
    - Pregnancy screening tests and the availability of scans.
    - Hospital processes and what is expected to happen at different stages of care including care on the postnatal ward and discharge processes and care after birth.
    - Availability and promotion of antenatal classes to address some gaps in information.
- Information to be available in different community languages and easy read with simple English.
- Women should be supported to have a birth plan reviewed regularly and jointly with women to take account of changing clinical circumstances.

- Improved provision and promotion of interpreting services for women who need it.

Continuity of carer

- Care provided through a named midwife (or a team of 2 midwives) providing opportunities for women to build trusting and supportive relationships with health professionals and to receive personalised care.

A review of staff attitudes and practices to include:

- Training to challenge negative staff attitudes including equality diversity and inclusion training, the role of unconscious bias and what constitutes non-stigmatising care, and equitable care. Training could include stories through SEL LMNS commissioned projects.
- A system of regular reflective practice focusing on how staff interactions, beliefs and biases can impact experiences of care.
- Training to enable maternity professionals to understand the challenges associated with using maternity care services for pregnant/newly birthed mothers including those for whom English is not their first language.
- Staff maintaining professional standards during interactions with each other and with pregnant and newly birthed women/people.
- Cultural awareness training on feeding and caring for a newborn and other practices amongst different communities.
- Awareness training related to the rights of migrant entitlements to NHS care.

Staffing and ongoing quality improvement

- Staff shortages need to be addressed if the quality of care is to be improved during labour and birth and postnatally on the hospital ward to ensure women do not feel isolated or abandoned and their needs are met.
- A systematic approach to reviewing service provision and ensuring ongoing quality improvements.
    - Promotion of opportunities for women to provide feedback about their care.
    - Case reviews when women report traumatic experiences and/or perceive their care to be negligent.

Care after birth

- The provision of nutritionally balanced food for women during their stay in hospital and food that takes into consideration of clinical circumstances.
- Consistent postnatal care appointments taking place in a timely fashion after discharge.

- Women are asked about their health and wellbeing and that of their baby at each postnatal contact in line with NICE guidance on postnatal care.
- Signposting and referrals for relevant physical and emotional support where needed and are followed up.

Working collaboratively with other services

- Maternity services to leverage partnerships with voluntary and community organisations supporting pregnant and newly birthed women/birthing people from diverse backgrounds to enhance service provision and raise awareness of and signpost women to available community support groups.
- Joint working with social services to ensure maternity care for women with a learning disability is a supportive process and to minimise delays in processing paperwork when women are being discharged from hospital.