

Learning from bereaved parents

Mehali Patel and Julia Clark discuss the Sands Listening Project, and what was learnt from the experiences of Black and Asian bereaved parents

Sands is committed to reducing inequalities in pregnancy loss and baby deaths. We believe that listening to parents can save babies' lives. In the UK, around 4800 babies are stillborn or die within their first 28 days of life (Office for National Statistics, 2023).

Over the past 10 years, UK stillbirth and neonatal death rates have generally declined, but families from Black and Asian backgrounds remain more likely to experience pregnancy loss or the death of a baby compared with White families (Draper et al, 2023). If between 2017 and 2021, the rates of stillbirth and neonatal death for Black and Asian babies had been the same as for White babies, 1704 more babies would have survived. No baby should be at an increased risk of dying because of their ethnicity.

There are many complex factors that can affect an individual baby's chances of dying. However, the accounts of Black, Asian and mixed ethnicity women and birthing people indicate that systemic issues and discrimination contribute to unsafe maternity and neonatal care for some families (Birthrights, 2022; Muslim Women's Network UK, 2022; Peter and Wheeler, 2022).

Sands Listening Project

The Sands (2023) Listening Project directly asked Black and Asian bereaved parents about their experiences of maternity and neonatal care in the UK. Through interviews and focus groups, 56 Black or Asian parents, whose babies had died at any

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stage during pregnancy or within 28 days of the birth, shared their stories. Focusing on experiences since 2016 allowed the project to learn more about what care is like today. With this knowledge, Sands aims to support safer and more positive experiences and, ultimately, save babies' lives.

Half of the parents who took part believed that they had received worse care or been treated differently by healthcare staff because of their ethnicity. A further group of parents described feeling unsure about the role their ethnicity had played in their care and whether it could have been a factor in their baby's death.

Some of the participants shared stories of excellent care, examples of which are included in the full report to acknowledge the commitment, sensitivity and skill of many healthcare staff. However, participants also spoke about care that was unsafe, with tragic consequences for some families. It is important to learn from these experiences because such practice has clear potential to contribute to inequalities in maternity outcomes and experiences.

In this project, parents described a range of safety issues that spanned their experiences of maternity, bereavement and neonatal care. They are shared here under four key themes that relate to fundamental principles of safe care: being listened to and heard; personalised joined-up care; communication about safety and risk; and safety and learning after a baby dies.

Being listened to and heard

Over half of the parents described healthcare staff dismissing them or not listening to their concerns, with some linking this to racism or stereotyping. Several Asian parents described how staff failed to take their concerns seriously because of stereotyping of Asian women as overly-anxious or high-maintenance.

A number of Black and mixed White and Black mothers described how the stereotyping of Black women as 'strong', 'dramatic' or 'feisty' led to their pain and distress being dismissed.

One mother, of mixed White and Black Caribbean ethnicity whose baby died after being born at 26 weeks, explained how midwives had failed to recognise when she was at her most vulnerable.

'I think they just could not recognise in me actual fear. They just saw this feisty, strong, brown woman. And actually I was so scared I couldn't speak...And they kept saying stuff like, "You're so brave. You're doing so well, you're so brave". And I just thought, you haven't even asked me if I'm OK. Because if you had asked me, you would know that I am not OK. And that this is not bravery, this is fear'.

Personalised, joined-up care

Parents also spoke about poorly co-ordinated care, involving many different healthcare staff, which contributed to delays and errors. Some described feeling 'lost' in a confusing system, with information about them and their baby being missed, mis-documented, or not communicated across teams.

Some parents felt that they faced additional barriers to building trusting relationships in such a fragmented system. They explained that it could be harder to connect with healthcare staff because of hostile attitudes and stereotyping from some staff, as well as their own fears about the views that staff might hold about families from their religious or ethnic background. One mother of Asian/Pakistani ethnicity whose baby died in pregnancy at 31 weeks described her feelings whenever she met a new midwife.

‘Every time I’ve had a new midwife through my pregnancies, the initial kind of meeting always feels a bit weird. Because of being an ethnic minority, and also Muslim and the way I dress. But... once that initial kind of thing is over then it’s OK’.

Communication about safety and risk

Many parents reported that they were not given the information that they needed about safety and potential risks, including about how their ethnicity might affect their pregnancy and the care that they were offered. For some, this meant that they did not have the information they needed to raise concerns or make informed choices about their care.

Some parents described feeling anxious when their ethnicity was highlighted as a risk factor by staff, but did not lead to enhanced care. Others reported that they had met dismissive or fatalistic attitudes among healthcare staff in relation to baby deaths and pregnancy loss in women from their ethnic background. These experiences raise questions about the effects of raising staff’s awareness of ethnicity-related inequalities in baby loss, but not providing clear guidance on how families should be looked after to mitigate against them.

Safety and learning after a baby dies

Many parents said they were not involved in any review, investigation or complaints processes after their baby died, although the reasons that they gave for this were varied. Some were unsure whether there had been any review of their care. Others had not wanted to engage with a system that had failed them and take part in a review that they perceived would have little benefit for them and their family.

Where parents did describe a review taking place, most shared negative experiences linked to complex and ineffective review processes, errors and delays, poor communication and a lack of candour and support. Some parents felt that their earlier experiences of being dismissed made it hard for them to

trust that the hospital would now listen to them, believe their experience and prioritise finding out the truth about what had happened to their baby.

One mother of Asian/Pakistani ethnicity whose baby died at 30 weeks described her reluctance to complain about her care.

‘Where is my proof? What am I going to say? How do I raise it? And again, it’s about bringing up something that...I’ve had a horrible life-changing experience, quite traumatic. But then, it’s like fighting, isn’t it? It’s like fighting. It’s like fighting for something that no-one’s going to believe’.

It is vital that healthcare staff listen to parents both during pregnancy and after a baby dies. When parents’ voices are not included in review processes, opportunities

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to understand what went wrong are limited and safety initiatives risk focusing on what healthcare staff perceive to be the problem. Underlying causes, such as discriminatory attitudes and practices, may remain unseen, perpetuating inequalities and contributing to avoidable deaths.

Conclusions

Addressing inequalities is everyone’s role and it is a challenge to us all. The Listening Project report outlines specific actions that UK governments, professional bodies and regulators and the NHS can take to make care fairer and save babies’ lives. But there is also an urgent need for staff on the ground to be supported and given the time, knowledge and skills they need to listen to parents; structure care to allow good communication; develop

detailed, personalised risk assessments; and support parents to contribute to reviews and investigations.

At the heart of this report are the babies who have died. For each person who told their story, the loss of their child or early end of their pregnancy caused immense pain. This report shows that the voices of some Black and Asian parents still go unheard. Their perspectives are critical opportunities to learn about how maternity and neonatal care can be made safer and more equitable at every stage. **BJM**

Read the full report at www.sands.org.uk/listening-project

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