healthwatch West Sussex

MATERNITY LISTENING PROJECT

February to June 2015

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Healthwatch West Sussex is a Community Interest Company limited by guarantee (No. 08557470)

About the project

From February to June 2015 our engagement team visited 8 parent and baby/toddler groups (with 3 further groups planned for Crawley before the end of summer) to hear what parents and carers had to say about local maternity services. The listening project was devised so local voices could inform the national NHS England focus on Maternity and local commissioning.

We would like to formally thank all the groups for welcoming our team and letting us speak to the parents who came to them and to the volunteers who supported us through this project.

The groups we attended were a mixture of independent community-led groups and those run in partnership with the Children and Families Centres. On the whole, the independent groups provided the opportunity to collect fuller stories, which in part could be due to the nature of the groups' settings and because the attendees were expecting us. Attending the Children and Families Centres allowed us to reach a wider geographic area but, as our events were held during baby weighing times, many parents were rushed or preoccupied. They did however allow us to reach a wider demographic as the groups were more diverse.

We struggled to find rural groups to host us but will continue to reach out to these areas in future activities (a rural focus will be included in our priority work from July 2015 to December 2016) and we plan to visit parent groups and those surrounding Chichester – an addendum to this report is expected late 2015.

The groups we visited were located as follows:

Our learning

We discovered parents were more than happy to discuss often quite intimate details of their birthing experience. For many it was probably one of the first times they had accessed services in a hospital. And for those having their first child there was a confusing array of advice available from a variety of professional and voluntary sources.

We were very clear the stories could be about any aspect of their pre-natal care right through to the present, but the majority of participants chose to focus on the pre and antenatal care, the birth itself, and information and advice services straight after birth.

Due to this being a Mid/South county split, we found stories either related to the Princess Royal Hospital and Mid Sussex Health visitors, or Worthing/St Richards Hospital and Worthing Health Visitors. However, we had a few additional stories about GPs and A&E.

All of the parents we spoke to have had a baby in the last two years and a few made reference to previous experiences.

About the stories

We spoke to over 285 parents during the listening project and have received in excess of 100 informative personal accounts. In reporting the parents' voices we have also included those received independently of this project over the last 12 months.

While many parents had a fantastic birthing experience, many others are still traumatised by the experience and felt there were things that could have gone better. These include:

- staff listening to parents more (all settings)
- improving staffing levels (hospital settings)
- keeping staffing consistent (community settings)
- keeping advice consistent (community settings)
- having more time to explain to parents what is happening or what will happen (all settings)
- preparing parents for the things that might not go to plan (all settings).

Many of the incidents mentioned in this report may well be regular occurrences in a busy Maternity Ward but it should be recognised by providers that these are new experiences for parents, and therefore can be scary and, for many months after the event, still prey heavily on the mind of the parent.

In most cases it was clear that many if not most of the parents we spoke to were ill-prepared for the things that might not go to plan and this was naturally more acute for first-time parents.

About the sections

This report is divided into experiential sections, rather than by settings. This has been designed deliberately to encourage readers to use this information to support reflective learning, and to understand what has the potential to make having a baby a good experience or a bad one.

Healthwatch West Sussex will provide breakdown information to each provider and commissioners, which will include more of the anonymised individual stories.

The Stories

What good feels like

Parents told us how individual professionals made their experience of giving birth a positive one, describing midwives and doctors as: *very supportive, encouraging, incredible, brilliant* and *amazing*.

'The midwife who delivered my baby was lovely and we had a peaceful first night in a single-occupancy room. She was great at explaining what was happening and keeping me on track during labour (it was fast and intense).' Afterwards the mother told us they felt there was support if needed but as this was their second baby, *'it was nice to not be bothered, if not required'*

Innovations and caring go a long way according to parents we spoke to:

'My partner could stay for first night, which was something being trialled. It has to be something kept!'

A mother who had given birth in another hospital said it would have been really helpful to have had her partner stay after her C-section to help, as the pain made it difficult to move to look after her baby

'After the birth procedure, both the consultant and anaesthetist came to see me, which I thought was impressive.' The parent wasn't sure if this was standard procedure or not. *'The aftercare was brilliant'*, as they had an understanding GP who referred them to hospital to get the treatment they needed

The hospital was very diligent and the booked C-section was brought forward to relieve the mother's fear

'I had a great deal of support with breastfeeding during two days I was in hospital. I was monitored and checked on regularly to ensure I felt comfortable with feeding my baby. I have continued to breastfeed for 15 months and feel a lot of this is due to a supportive start'

Expectant mothers told us how important it was for midwives/general practice staff to find time to talk to them, particular when something changed.

'I moved from London when I was 7 months' pregnant. The transition went really well as the local midwife phoned and chatted with me'

'My baby was breech and wouldn't turn, so a planned caesarean was booked. Birthing plan was made with the caesarean at the centre. Staff were extremely supportive as I don't like needles and they supported me through this fear'

A mother praised a general practice, for their '*fantastic nurse phone back service which always put my mind at ease*' and that they will see her young children the same day if necessary

Preparing parents for the realities of the birth experience

The drive towards personalised care is an important one for maternity support and it is clear from parents that one-size support does not work for them. For example one mother told us how it '*would have been nice to meet other midwives when having a home birth'*, whereas another *'preferred to have one midwife and not a team'*.

Creating a calm and empowering environment is important. We heard from mothers about how ante-natal appointments felt rushed and the community midwife always seemed busy, which led women to feel '*prevented from asking questions'* and *'did not leave them feeling confident'*.

One mother told us she felt there were too many staff changes. They *'didn't see the same midwife twice, which lead to a lack of effective communication'*. With increasing demand on maternity services it is becoming more likely that expectant mothers will see multiple midwives throughout their pregnancy. Preparing an expectant mother to this early, and giving guidance on how they can be an active partner in the communication, may help reduce some of the impact a lack of consistency may have on people.

Parents provided examples of where more information before delivery would have helped:

'I was turned away from hospital three times before being admitted. The last time I had to insist. I was then discovered to be 6cms dilated. Once admitted the care was excellent'

Due to the baby's irregular heart-beat the mother had to lie down with a monitor on, which she found uncomfortable and she said she didn't feel it was necessary to lie down

Having had a planned C-section a mother was told on discharge they were supposed to have blood thinning injections. They were sent home with these and their partner had to support without either of them have had any training

Specific preparation needs

A parent, who does not hear and was unable to make it known she could not hear as she does not sign, shared her traumatic experience of giving birth to her second baby. She told us she had got into the birthing pool but felt uncomfortable so got out but felt vulnerable because she wasn't able to get her point across about the pain she was in. As the baby's heart beat dropped, staff asked them to say when next contraction came, to which the mother said okay. However, the doctor (whose first language was not English) took this as a contraction and started pulling on the baby. The deaf parents were horrified but it was clear they needed to get the baby out.

The baby's arm didn't move and unfortunately the baby has been left with Erb's Palsy. The mother felt the hospital had not really looked at her birth plan and feels the doctor '*just did their job*' without attempting to communicate with her.

This is an example of how care must be taken in order to put in place methods for communicating with parents, and ensure all staff understand any specific challenges for the parents or the staff.

Disability, Pregnancy and Parenthood International have an article for supporting people:
http://www.dppi.org.uk/journal/69/goodpractice2.php

The RNIB provides information in relation to pregnancy for visually impaired mothers-to-be:
https://www.rnib.org.uk/information-everyday-living-family-friends-and-carers-resources-blind-or-partially-sighted-parents

Expectant mothers as experts in their own needs

Whether due to pressures on maternity wards, or communication issues, parents told us how they felt they were not listened to and how this had a negative impact on their birthing experience.

A parent told us the ward staff were extremely helpful but they had found others rude when they had called to be admitted, being put off from coming in as contractions weren't regular. They took themselves in and were 7cms dilated on arrival. About half an hour later, they bled and were rushed into theatre. They feel that had they not chosen to go in hospital when they did, the outcome could have been a lot worse. When they got to theatre they were told by the midwife that they had '*done really well to stay at home for so long*'

As the mother's waters hadn't broken and the parents felt that the labour at home midwives didn't listen when the mother said about their labour advancing. In the end their partner took them to hospital where they were triaged. The mother described the 3 internals she had as '*brutal*' because their labour was so advanced. They were taken to the delivery suite, where their baby was born within minutes

We spoke to a number of parents who had experienced giving birth more than once and the clear message given was that professionals need to be prepared to listen more to experienced parents. '*I feel the labour ward midwives should listen to parents more if it isn't their first baby. I was told I was 1cm dilated and to calm down and my baby was born 45 minutes later.*' This mother felt the midwife made it more stressful than it needed to be.

A parent having their fourth child was not fearful about the birth but told us they felt they had not been listened to during the birth. They had kept saying something was wrong, as they felt in too much pain but were told by nurses that they '*weren't pushing enough*'. A consultant who appeared in the room said straight away that they needed an emergency caesarean as the baby was in the wrong position.

How it feels when high demand or staff shortages occur

Parents shared their experiences and feelings when their birthing experience happens when maternity services were under pressure.

A parent described how they felt ignored, having been left alone for 4.5 hours on the prenatal ward. They ended up giving birth there, rather than in a delivery suite. Added to this, their notes were wrong and they did not get the rubella injection they were supposed to receive

A mother wanted to try breastfeeding but '*there wasn't any support'*. They were told that before they could be discharged they had to '*prove'* five times they could breastfeed successfully. They feel that if they had chosen to bottle-feed they could have got out sooner. The mother also felt they could have got better support for breastfeeding from the community nurses

A mother had assumed they would be discharged by 4pm and therefore didn't plan to have dinner at the hospital. Their observations came back fine but they had to wait on their notes and medication. They were still in at 7pm and started feeling ill as they hadn't eaten, were agitated by the heat and noticing others were being discharged. '*It felt like those who shouted the loudest got discharged first*'. They were told it was an extremely busy 24 hours and they hadn't had the time or staffing levels to cope with all the demands

A mother was induced and said '*it was a terrible experience'*, as they were not monitored at all during labour as staff didn't believe the mother was having contractions. The mother was told to '*pull myself together even though the baby was coming out'*. They gave birth in the post-natal ward behind a curtain during visiting times

A mother, who had been experiencing contractions for several days, had to wait for labour to be induced because the delivery suite was busy. Once induction had started their labour began slowly. The baby's heartbeat was very low but steps to increase the speed of labour weren't taken because the department was still very busy. After an emergency caesarean, the baby was taken to the special care unit and given antibiotics. The mother was told her baby had suffered a fit due to oxygen deprivation during labour

It took 12 hours to be discharged and during this time, the mother had been unable to get any water to take some tablets

Creating the right environment for parents

Some of the people we spoke to during our project choose to tell us about issues with the hospital environment from basic things like hospitals not having enough pillows to issues such as the wards being too hot. Here are some of the comments to consider:

'I had my baby in the evening. There were two parents on the ward and by the morning the ward was full. Ward was really warm, too hot and it was making parents feel faint'. They opened the window and they were told that parents could go into the feeding room to get away from it but the other parent wasn't allowed to accompany them. *'Fans were requested but there weren't any'*

A mother had to be in hospital for 7 days in July but was not allowed to leave to collect appropriate clothing for the heat

A mother said they thought reclining chairs should be given to C-section mothers first

Importance of getting quality treatment and care

We heard some personal accounts which suggest some of the quality of care and treatment parents receive was less than adequate and these are detailed in the individual provider reports.

However, there are lessons that can be learnt across maternity services from the examples below:

A parent questioned why there wasn't a saturation monitor on the ward, so staff can monitor oxygen levels in babies. This was something available at their GP surgery

A mother had an emergency caesarean and whilst they felt the staff were very good at keeping them calm, they changed their minds about whether a caesarean was needed a number of times, which they found '*annoying'*. When the mother went onto the ward, they asked a staff member if they could get some warm water so they could change the baby's nappy as the mother was struggling with the pain from the operation.
The answer they got was '*why can't you get it yourself*'.

A mother who had previously had a caesarean delivery was pressed very hard in the stomach by a nurse, who was unaware of her history. The mother felt they should have consulted the medical notes

A parent felt it took a long time for it to be agreed by the hospital that her baby was unwell from birth (as baby was having problems breathing and feeding). The parent kept being told everything was fine. There is now a diagnosis and their baby is under the hospital's care. Since then, the care has been really good but they feel if they had been listened to sooner, things would have been easier

When baby had a low heart rate, the family were sent straight to hospital, which they felt was great, although they were given the news in an abrupt way and then had to drive themselves to the hospital when they were shaken

Accessing support in the community

As well as hearing positive accounts about community based services, we heard others that should be considered by providers and commissioners.

A number of parents told us they were wondering why there was no community midwife in Hassocks, commenting it is expensive and difficult to get to The Gattons Children and Family Centre (Burgess Hill) if you do not drive, as there is no direct public transport (Google maps state a 20 minute walk on top of the bus journey). One parent said '*having to travel to Burgess Hill for a midwife is a negative experience*'.

Some parents spoke about the support from an individual health visitor as being '*great*' but in general, the parents we spoke to have found the health visiting advice to be patchy and inconsistent. For example, the health visitor advice in Hassocks does not match national guidance, including weaning before 6 months, no advice on baby-led weaning, and sleep advice out of date (advice given to 'cry it out').

'I felt cornered when I disagreed with advice and ended up avoiding health visitors. Advice also seemed mixed depending on who you spoke to'

A mother felt the Health Visitors *'ticked things off their assessment checklist without even discussing them with the parent'*

Having the right conversations

It is important professionals provide person-centred support and in a non-judgmental way.

A mother was asked by a community midwife, on having their third child, *'so has this one got the same father then*?' The mother, who is in a long term relationship with the children's father, feels this comment was levelled at her because they had not chosen to get married, and they are relatively young and live in an area with more older-mothers.
The midwife went on to say *'Well I think I'll send you for a chlamydia test anyway'*.

A mother told us she felt judged by her Doctor for being pregnant with their second child as there is a 13 month gap. Doctor asked if they hadn't taken contraception

A week after the birth a midwife checked a mother's stitches as they were in so much pain, they said they were fine. Due to the pain the mother went to see her GP later that day, to be told there was an infection

A mother was breastfeeding and for 12 days their baby didn't defecate. They asked the health visitor if this was a problem and were told not to worry, the baby was fine. Not satisfied with this, the mother took their baby to the emergency doctor who prescribed laxatives but after 48 hours the laxatives had not worked and the baby was losing weight. The mother decided they were not getting enough milk, so went on to formula. Their baby started defecating and gaining weight straight away

A mother described how she went into labour and after having moved back to their bedroom could not move. Her husband called an ambulance but they didn't know what to do and asked if they had rung the midwife. They hadn't because they didn't think they needed to. The midwife arrived and their baby was born within a few minutes. The midwife had to go back to the hospital to collect items in order to be able to stitch the mother

A mother told us how she had been breathless and complained of feeling ill to community midwife but this was not picked up. She became seriously ill and is now on blood thinning injections. The mother feels lucky it was caught before being fatal but believes the midwife should have taken action earlier

We also heard how a couple of tongue ties were missed and we understand commissioners are aware of this and are taking action.

For the benefit of parents:
NHS Choices state a tongue-tie (*ankyloglossia*), which effects 4-11% of babies, is a problem affecting some babies with a tight piece of skin between the underside of their tongue and the floor of their mouth (lingual frenulum). It can sometimes affect the baby's feeding, making it hard for them to attach properly to their mother's breast. The treatment for this is described as '*simple and almost painless procedure that usually resolves feeding problems straight away*'.

http://www.nhs.uk/Conditions/tongue-tie/Pages/Introduction.aspx

Next Steps

Healthwatch intend to discuss with providers and commissioners how each will use the accounts within this report to enhance their work and practice and will follow-up with providers on individual recommendations. We will discuss the report content with the Mid Sussex Maternity Services Liaison Committee to see how this can influence the development of service provision.

We plan to update our findings and report on how services and individuals have used this information and expect to have an update document ready for publication in October 2015.