

## National Maternity Review Engagement and Outreach work with Gypsies and Travellers: Focus Group for NHS England

Michelle Gavin | Friends, Families and Travellers | November 2015

Several women were unable to attend the focus group at the last minute due to eviction proceedings taking place. There was a group who were subject to sec 61 proceedings in Brighton- this group had previously moved as they were evicted the previous night from Black Rock Brighton. Two Travellers were already in the nearest Transit site in West Sussex due to eviction action and were sectioned into the site in Chichester (too far to travel) and one Traveller was placed into emergency temporary housing in Peacehaven.

We went around the table and everybody introduced themselves and explained their own circumstances.

Marya Sadouni (MS) – A Romany Gypsy and FFT outreach worker and Doula nurse explained that on this morning she had been supporting a 16year old Irish Traveller girl on an unauthorised site in Brighton. She was on site helping the girl prepare for her imminent hospital stay as she was 34 weeks pregnant. Marya was helping her arrange her overnight bag and advice and support her with welfare, benefit issues and also giving her answers to questions about what to expect when she arrived at the hospital. During her visit the Police arrived to inform the encamped Travellers that the local authority had asked them to use their powers of eviction under sec 61 of the Criminal Justice Act. The Local authority had asked the police to evict the camp from the car park adjacent to some playing fields where apparently there was to be a football tournament the following day. MS explained that this girl and her family had been subject to 3 evictions over the last 2 weeks and the cumulative effect on her health and wellbeing and that of the babies was suffering due to stress and uncertainty. The young woman was very anxious and scared that she would not be able to find another place to encamp near to the hospital and where she would be able to camp on hardstanding ground.

P2 - an English Gypsy with 7 children and 16 grandchildren explained that she too was encamped on this carpark with her daughter (who was sitting next to her) Her 17 year old daughter P3- was 4 months pregnant and was also being evicted. She explained that her daughters 1st baby is due in April and it is extremely unsettling for her to be moved so often from pillar to post by the Local authority. P2 explained that P3 had been taken into hospital twice already with issues around the pregnancy. The second time she was taken in (a few days before) she was found to be dehydrated and was placed on a ward and given rehydration drips until she was deemed fit. She was released at 2am in the morning from the ward.

Michelle Gavin (MG), FFT, explained that this was not unusual and that many Travellers suffered with similar issues if they were 'roadsiders living on unauthorised encampments with no access to running water or toilet facilities.

Zoe Matthews (ZM), FFT, explained that FFT are currently working on a discrete piece of work around bowel /bladder and incontinence issues within the Traveller Community. She explained that

Gypsies and Travellers would not use a toilet within the caravan accommodation because it is not seen as hygienic to toilet in the home where you live and cook etc. This leads to Travellers using public facilities, petrol stations and supermarket toilets.

MG went on to explain that this will often result in many women not drinking enough fluids when pregnant because they were not close to any public facilities and when pregnant it is very much harder to 'hold on' when the baby is pressing on the bladder etc. MG explained that some Local authorities will provide a portaloos on unauthorised encampments at the last trimester of pregnancy.

P3 agreed that it was difficult keeping hydrated because she was not in an area close to a public toilet- and the toilet nearby at the petrol station had been out of order.

P4 explained that she had been given a toilet on an unauthorised site but when the camp had been evicted and moved on to another site the local authority did not deliver another toilet because they could not get access down the track and would not place the portaloos at the end of the track for use. She went on to add that for the last few weeks of her pregnancy she had no toilet on site at all.

Everyone agreed that at some point when they had been on the roadside they had all experienced or knew other Travellers who had experienced issues around need to use toilet facilities and how it had impacted throughout the pregnancy.

P3 said that she was under the Traveller midwife in Brighton's Sussex County Hospital. She had been to her first meeting which had taken 1.5 hours. This opened up the discussion about ante-natal care. Several of the women said that they did not feel that they were given enough information about options and choices. Several women said that at the first meeting it felt like a tick box exercise and that a lot of what the midwife asked or said just went over their head. They felt rushed and not truly informed. There was too much jargon.

P5 explained that she had been given little choice around her Midwife and had been allotted the midwife for young people. She explained that she became pregnant at a young age under difficult circumstances. She added that the midwife went through the questions without any care to her emotional situation and the question around domestic violence was left in when it should have been removed. She said she felt judged by this midwife and also the midwife had breached confidentiality with another expectant mother talking about her circumstances. The whole experience had made her feel very let down and not supported. She felt that she had been judged differently and treated differently by this NHS staff member because of her Traveller heritage. P5 was supported in making a complaint about this midwife by her health visitor. An apology was received from the midwife as a resolution.

P4 also said that initially she had been given a young person's midwife but it had flagged up issues because the midwife had involved children's services because P4 was living in a trailer on an unauthorised encampment. FFT had intervened in this case and the social worker had been advised around cultural awareness and competency. FFT also arranged for P4 to have a Traveller midwife take over as her midwife- which P4 reported that she felt more supported and not judged and it was a much better experience.

P6 said that when she was pregnant with her second child she had been living in West Sussex in a flat and her midwife visited the home. P6 explained to the midwife that she was leaving bricks and mortar and returning back onto the road in her trailer. P6 had lived most of her life on the road from birth to adulthood – with a few brief interludes in bricks and mortar. P6 felt isolated in the flat and needed to reconnect with her community. The midwife was visibly horrified that P6 was to leave the flat and immediately contacted social services. P6 said that it was very upsetting having to explain why she wanted to go back to living in a trailer with her community. This issue was not resolved until P6 came into Brighton and was linked in by FFT with the Traveller midwife in Sussex County. The Traveller midwife liaised with the social worker who had been passed her details from the other county and explained that it was pertinent for P6 to live in a trailer with her children. The case was dropped in Brighton but it left P6 feeling that she had been treated in a racist manner by NHS midwifery staff and judged as a result of her Gypsy culture alone.

P1 experienced issues with staff in hospitals with her pregnancies. She said that staff had been very aggressive and refused to allow members of the family/ community on the wards after she had given birth to her children in at least 3 hospitals. She explained that staff did not understand why so many different members of the community wanted to visit after the birth of a child and they did not understand how important it was culturally for the community to welcome the new-born. This resulted in people being turned away from the wards. However P1 said that one hospital was completely different and welcomed everybody and helped the community to celebrate – very inclusive and friendly in Durham.

Another Traveller P7 spoke on speaker phone from another location and told her own story. She was carrying twins and had booked in at Sussex County Hospital in Brighton for a caesarean- however she was travelling at this point and not yet back in Brighton for the due date. Her waters broke and she was alone so she drove to the nearest hospital in Hastings East Sussex. She presented at the hospital and was told in no uncertain terms that she was booked in at Brighton and she was very rudely sent away and told to go to Brighton. P7 left the hospital and drove alone 100 miles to Brighton with broken waters and carrying twins. She said as soon as she went to Brighton she had a brilliant experience. P7 believes she was treated badly by Hastings because she was flagged up as a Traveller.

Everybody had strong opinions on choice of midwife and several women stated that they were also unhappy with the midwife they had been given but did not realise that they could ask for a different midwife.

MG and ZM both had the same midwife deliver each child. This was on both occasions by chance- but both said that the experience was excellent because of the continuity of care and knowledge of the parents and lifestyle.

P8 had a very long labour with her second child. She explained that she did not like her midwife who she felt was rude and judgemental. She said she was very bossy and kept making her get up and walk around when she was clearly exhausted (the labour was over 16 days on and off) P8 believes she probably went out of labour because of the midwife and how the midwife behaved towards her

– she felt that the midwife was looking down on her. When she stopped labour and left the hospital to go home she felt more in control. The next time she went into the hospital the midwife was completely different and she felt comfortable – the baby came without incident because she relaxed and worked with the midwife.

P8 also said that her original midwife had come through outreach service and visited her at her home on an authorised site. P8 had attempted to contact her several times to ask her not to visit at home at the three month visit because she did not want anybody else on the Travellers site to know that she was pregnant at that stage. However the numbers she had been given just connected her to the birthing ward at the local hospital and any messages she left were either not passed on or ignored because one day she turned up with another health visitor at the site to pay P8 a home visit. After this visit everybody had been alerted to the fact that P8 was pregnant P8 felt that at this point she had ‘lost control’ of her pregnancy. P8 said that she didn’t feel in control of her pregnancy from this point.

P1 said that she felt that her midwife had not explained anything to her and she was not talked to about her options. She also said that she was not told about her options for pain relief- didn’t know what an epidural was and had no idea about the injection given to help evacuate the after birth or VIT K injection for baby. P1 said that you are now expected to read all the information that they give you on the first appointment. P1 said that pregnant mums are meant to look at all the information and do their own homework. P1 said that many people from the Gypsy and Traveller communities have problems with reading and writing and also understanding. There is always too much jargon and many Travellers struggle with the amount of information’s passed to them.

P3 said that she can’t read and write and took her Mum with her to the appointment with the midwife. P2 said that she had gone with all her children and sat in on the appointments and also had been present at all of the subsequent births of her grandchildren. She felt that information about epidurals was not explained properly. She gave an example how one of her daughter in laws was given an epidural and then didn’t know at what point to ‘push’ because she could not feel any contractions. This woman had previously had a caesarean section for her first child due to complications and for the second birth she wanted to birth naturally. She struggled because of the epidural. P2 felt that all of this should have been explained right at the beginning.

P9 said she didn’t get offered any pain relief until she was screaming for it. She wished she had known about epidural because she felt the pain traumatic. She eventually gave birth in water.

P10 is currently pregnant and she has a 5 year old- she told her story about how she had a bad experience because of a lack of data sharing between several hospitals. P10 at this point was highly mobile Traveller and felt lack of data sharing left her in a very bad position- even though she was carrying hand held records. The information was poorly shared between Royal London - Honiton and Sussex hospitals. She had preëclampsia and was very sick so this really affected her experience.

P10 was born on site and her Mum gave birth to all bar on one of her 6 children at home in her caravan. She gave birth at different sites around the UK. Only one child was born in hospital- and this was because it was so rural that NHS could not send anybody out.

Her Mum always said that home births were better but P10 decided to give birth the first time in hospital. She has also decided to give birth to her next one in hospital. She said that when you are at home – it's like the trailer door is always open and people would be in and out every second. She also has chosen not to have her partner present at the birth preferring privacy and her mum with her.

P2 said that none of her children would give birth with their partner or with a man in the room. Instead they are supported by her or a sister. It is very rare culturally for men to be present at the birth for Romany Gypsies and Irish Travellers. MG said that her Irish Traveller husband had been present at the birth of her two children- although she conceded he had very modern ideas. MS said that she had heard of more men joining their wives in the labour room but it was still culturally not usual nor pertinent and that child birthing was definitely a woman only domain.

P9 said that she was too scared to have her children at home and preferred the hospital -although she said at the birth of her first child there were issues. P8 was very anaemic and haemorrhaged. She lost so much blood that she had 2 blood transfusions. She had to stay in hospital but the father of the child was unable to stay with her and was sent out at 11pm in the evening. P8 had travelled a long way for the birth – many miles from her site and therefore the father could not return home. He ended up sleeping in the hospital car park in freezing conditions overnight.

MS said that there were better facilities now and that husbands are given opportunities to stay over with their partners. MS said that there were reclining chairs and Baroness Julia Cumberlege (JC) said that she had now seen many double matrimonial beds on wards now.

P10 mentioned that she had been very disappointed by her midwife who immediately after she had given birth stormed in and started to give a long lecture on breastfeeding. She made huge assumptions that just because P10 was a Traveller that she would not be breastfeeding her child. At the end of her long tirade about the benefits of breastfeeding and the negative thoughts the midwife had about people who didn't breastfeed P10 told the midwife that she was planning to breastfeed her child- just as her mother had done before her. P10 felt that she had been judged and the midwife had not even asked her if she had decided on feeding methods.

MG said that there was a general feeling amongst midwives that Travellers do not breastfeed or use own milk but instead employ bottle feeding. MG pointed out that recent research and FFT own research had shown that attitudes were actually fairly neutral and a piece of targeted work around feeding prior to birth would/could improve take up of breastfeeding rates.

P4 said that she wanted to breastfeed and was not given advice at the time of birth. She tried to breastfeed but the baby was not latching on. She said that she asked for help but there was no one available to instruct her. She kept on trying and was sent home. The baby then subsequently had jaundice because he was not getting any /enough milk at home. FFT support work made several appointments with breastfeeding peers etc. and specialists, all of which were cancelled by NHS staff. Eventually she used a pump – however NHS midwives did not understand that P4 did not have access to electricity on unauthorised site for the whole day. In fact P4 had to use the pump when the

generator was turned on during the evening for the small window of time. P4 felt that if she had been instructed immediately then she would have not had to go through this pump system.

P10 said that it would be a good idea if midwives explained the implications of using bottles when you are living in a trailer. Having to sterilise bottles, have a large supply of water for boiling etc, and how it makes more sense to breastfeed or at least combination feed.

Several of the women said that they had combination fed. One of the issues about breastfeeding was lack of privacy in the trailer as people were always coming in and out to see the new baby and there was nowhere to retreat to feed privately except at night. So several women expressed and fed exclusively by breast at night.

P9 said that nobody explained that you had more options other than to just breastfeed or bottle. P6 said that it was a good idea if midwives explained about combination feeding.

JC asked if the group had or knew of anybody in the community who had experienced a still birth and anyone who had experienced or knew of baby blues.

MG spoke of several of FFT clients who had experienced the trauma of still birth. One client had experienced a very traumatic still birth in Leicester– some members of the family felt the aftercare was not appropriate. The lady had suffered with extreme anxiety and depression afterwards and had been a victim of a racist attack on an unauthorised site shortly after this. A brick had been thrown through her trailer window and landed inches away from her only living child. This experience exacerbated her depression. Unfortunately in this instance the client was so terrified that she returned to another site after being evicted from it several days before. Lack of understanding from the local authority and Police resulted in the woman being arrested for breaching an eviction order FFT had to intervene and the woman was eventually released from police custody.

P5 spoke of how as a child women would disappear to give birth to their children and return alone. She explained that no adults had explained to the children what had happened. But she said it was not uncommon for women to experience still births.

P2 said that she had one still birth and she had suffered depression after this. P1 has also suffered with 2 still births and several miscarriages.

MG said that she had recently spoken with a colleague who had been working with a Traveller who also had suffered extreme depression after a still birth. According to national figures Gypsy and Traveller women are more likely to suffer the loss of a child.

All of the women knew what baby blues were but none of them had been told about it before they gave birth. Several of the women only realised that they were suffering with this after they had gone through it. P5 said that she was not told about this problem and felt different from other Mum's. P8 said that because she had suffered with baby blues after her first child she was a little dismayed to see that the mental health nurse was appointed to her immediately after the birth of her second child. She added that she felt labelled.

### Summary of focus group

Generally the women agreed that it was very important to have continuity of care and be able to choose one midwife for throughout the pregnancy.

The women also agreed that for Travellers who were living on the side of the road on unauthorised encampments women should be helped with provision of toilets. This could be achieved through the Local authority public health budget in partnership with the local CCG. Expert letters from the midwives should carry weight if the healthcare professional recommends that the pregnant woman requires a porta loo in this instance.

It was agreed that traditional Travellers did not encourage or want paternal/male involvement in labour wards and birthing rooms. Although it was agreed that reclining chair facilities were important on the ward for overnight stays if necessary (for the partner)

It was noted that the level of homebirths had decreased over the years – however some of the women were interested in home births but felt unsupported or were ‘frightened’ due to attitudes from healthcare professionals.

It was agreed that the levels of written literature and the design of literature were not targeted for the Traveller population- many of whom have no or low literacy. Everybody agreed that there was too much jargon and perhaps more appropriate literature or more personalised approach which was not ‘tick box’ should be offered.

The younger women were all keen to explore breastfeeding options and generally felt unsupported or felt that there were preconceived attitudes by healthcare professionals about ‘Travellers don’t breastfeed’. The group agreed that feeding options should be an ongoing conversation with midwife and pregnant Mum.

The woman all reiterated that they had been subject to some type of prejudice or racism- whether perceived or real due to disclosure of their Traveller ethnicity or lifestyle. More cultural awareness appears to be imperative to improve this issue.

**The Focus Group:**

Ethnicity of Attendees: Gypsies 3    Welsh Traveller 1    New Traveller 4    Irish Traveller 2

Age: 41-50 =3    18-24=5    25-40= 2

Gender: All female

Accommodation

Private site=3

Unauthorised encampment= 4

Bricks and mortar=3

Of the women present- 2 were currently using maternity services.

Women in the room who had used maternity services as expecting mothers within last 5 years =5

Women who had experience of maternity services within last 5 years but not the service user =3



Results from the Questionnaire supplied by NHS England

Of the respondents:

Gender: \_\_ Women 90% Men 10%

Age: 18-24= 30% 25-30= 20% 36-40= 10% 41-50= 40%

Ethnicity: Roma 10% Irish Traveller 50% Gypsy 30% New Traveller 10%

When did you use maternity services?

Currently using services 40%

Used with last 5 years 20%

Use 5 years or more 40%

How involved did you feel?

Involved – 30% felt involved around decision making around care

Not involved- 70% felt that they were not involved or were disappointed with staff making decisions for them

Which of the following choices relating to your care were you given?(percentage who ticked yes)

Where to go for ante natal checks = 80%

Where to have baby= 60%

Kind of delivery=60%

Pain relief during labour=70%

Choice of how to feed baby= 40%

Choice of partner being able to stay overnight= 20%

Choice of single sex ward (no partners staying overnight=) not answered

Where to have post-natal checks=All GP

How Many post-natal checks visits =20%

Home birth =10%

Summary of respondents who would have liked more information

50% said they would have liked more information about feeding choices

30% said they would have liked more information about the type of delivery

How important is it for you to be supported by same midwife- before, after and during birth?

90% said it was extremely important (mark 5)

What went well?

*I asked to give birth in Dartford Hospital when I was told that the hospital near me had a bad reputation. I was very happy because my choice was listened to.*

*I was very happy with my hospital – Hemel Hempstead*

*Very happy with the Traveller midwife in Brighton- Travellers like to come to Brighton because they are treated with respect. Travellers book in from all around to have their children here.*

*I was afraid to give birth but I was supported and my choices were listened to*

What could be done differently?

*Lots of excuses were put in front of me to stop me having a home birth- I was keen to have a home birth but I didn't feel supported.*

*I would have liked my midwife to understand and respect my lifestyle as a Traveller. She seemed to look down on me.*

*I was not given any choices- I was just told to do this and do that. I was not asked about my thoughts. I just did what I was told. I wished they had talked more to me and asked me if I understand.*

*Tell me more – don't just think I can read about what I need to know!*

*I had a terrible time – I wanted more pain relief and nothing really went well. I felt judged because of my culture.*

*Talk more to me and ask me if I understand!*



## About us

Friends, Families and Travellers is a leading national charity that works on behalf of all Gypsies, Roma and Travellers regardless of ethnicity, culture or background.

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