Addressing Health & Wellbeing Inequalities: Community Insight

Report:
Turkish Speaking Carers Feedback on NHS

Antenatal, Intrapartum and Post Natal Care & Disability Services

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by
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Aims & Objectives

The main aim of the research project is to explore the views and recommendations of Turkish speaking parents with disabled/SEN children, on antenatal, intrapartum, post-natal care and disability services of NHS through questionnaires and case studies conducted by Minik Kardes Children Centre's community development workers.

The project is designed to collect evidence and to deliver the voices of this one of the most vulnerable group of Hackney citizens, by prioritising a patient centred care approach. It is intended that the research results will provide a good feedback and a structured evidence to improve available services and to provide better and more effective use of them.

Background

During the outreach community work carried out at Minik Kardes Children's Centre, a specific support need has been identified by Turkish speaking parents with disabled/SEN children using NHS services. As a result a parent forum has been established in June 2011 named as Turkish Speaking Carers Action Group (CAG) in partnership with Hackney Ark. The group members represent one of the widest ethnic minorities living in Hackney, having a language barrier on top of the disability issue, therefore seldom heard. To date, 19 meetings in total have been carried out on the subjects the members have identified, such as; on early diagnose, family therapy, NHS Patient rights and PALS, group therapy on anger management and acceptance, individual budget, housing etc. The subjects covered during these meetings had direct links to patient centred care. It has been identified that parents/carers are using the following services of NHS: maternity unit, GPs, Specialist Hospital, Hackney Ark, Mental Health Services, and many more health organisations.

Turkish Speaking Carers Action Group (CAG) members have reached up to 65 families. Each meeting had 10 to 15 participants. We also provided a 3 month volunteer pilot project providing 1 to 1 advice sessions for CAG group members. In addition to the meetings, drop-in sessions have been carried out by volunteer advice workers based in Hackney Ark. As a result of meetings and advice sessions, a solid background has been gained about the issues that the group is dealing with while using the services.

Research Methodology

Focus Group Meetings & Interviews

Two focus group meetings in June 2014 have been carried out as well as one to one interviews with 10 to 15 targeted parents/carers in most need, during a 3 month period between May and July 2014.

The main aims of the focus groups were to empower the group members to share views with others with a similar experience, allow their voices to be heard, identify the main issues and themes for the one to one interviews. The focus group meeting also included a discussion and feedback on the draft questionnaire.

Two focus group meetings was carried out on 24/06/2014 and 25/06/2014 at King Henry's Walk Garden. Prior to the meeting, a picnic was organised on the same day and location to provide parents/carers a peaceful and relaxing atmosphere, considering that the discussion potentially may raise difficult subjects which could be traumatic for most parents.

During both the focus group meetings and the individual interviews parents had the opportunity to explore and give feedback on which health services they think work well and which could work better for people experiencing disability in their family. Through this research, parents were encouraged to visualise how they would design the health services if they were given the opportunity to allocate the resources.

It was also often expressed by parents/carers that when a child was born with a disability, it is the moment family feels their life is not going to be an easy one. The research helped to understand what kind of early support should be provided to the parents/carers who have wide range of questions and concerns.

In total 11 questionnaires have been completed. Interviews were carried out both face to face and on the phone. One of the thirteen interviewees was a father the rest of them were mothers. Some issues in relation to the involvement of the fathers in the care of disabled children were raised by the mothers during the focus group meetings and questionnaire interviews therefore it has been an important input to include a father's point of view. Nevertheless, shortage of fathers' involvement in the research may also be considered as an indication of their general involvement in the overall care process of the children. One father involved in the process have stated that : "*I have used my own initiative and involved in every session but no one has invited me or encouraged me to get involved in the process, or gave me information about changing roles, responsibilities or what to expect*."

Questionnaire Design

Questionnaire was designed in consultation with the parents and carers. Health Watch professionals were also consulted during the design process of the questionnaires in order to gain feedback on the content of the questions as well as to evaluate the suitability of the questions for quantitative data analysis.

The questionnaire is consisting of three parts:

- **Antenatal Care**
- **Intrapartum Care,**
- **Post Natal Care & Disability Services.**

The questionnaires included sections for narrative case studies, as well feedback and recommendation sections in the form of free texts which have provided data for qualitative analysis. Questionnaires were gathered, anonymized and translated into English.

All of the parents mentioned in the case studies below are living in Hackney and gave birth to their children at Homerton Hospital.

Findings

Narrative Analysis

Case 1

- ***Neglect:*** *ignoring the evidences test & scan results done in abroad). Unjustifiable decisions to terminate pregnancy without a final check.*
- ***Barrier to information:*** *Not being aware of the patient rights (right for second opinion). Receiving all the critical information in second language.*
- ***Abuse of power:*** *GP records during the antenatal appointments are not kept safely and independently.*

"I am married to my cousin. I had a miscarriage on the 3rd month of my first pregnancy. I mentioned to the doctors that there were members of my family with down syndrome. At the beginning of my second pregnancy, I went under an early pregnancy scan in the UK within the first 3 month. As a result, I was told the risk of down syndrome was 1/835.

After completing the 3rd month of my pregnancy, I went to Turkey. I had another scan there. Not because I was not trusting NHS but I just wanted to talk to the doctors in my mother tongue. I wanted to get a second opinion. I got a scan and blood tests in Turkey. When I have received the results, the doctor in Turkey diagnosed "high risk of down syndrome as 1/67". He recommended an amino-synthesis.

When gave my doctor the reports and test results I brought form Turkey, the doctor got really angry and said that those reports were not accurate. He rejected the need for amino-synthesis and did not confirm it. I have been scanned again in UK on the 5th month. I was again told that everything looked normal as a result of the scan. The doctor gave us an assurance that everything was absolutely positive and normal with the pregnancy and the baby. I was not aware that I could get a second opinion. No one has told me that I have right to do so. I later realised that, nothing that we had discussed with the doctor that day had been recorded, or they had been deleted later. After 3,5 years, at the court hearing (where we lost the case), the doctor denied all the evidences we had submitted him, and the conversation between us, and he said he had never received any information from us as such and never had a conversation about risks we mentioned.

The only advice doctor has given me was that: "if the child does not move for 12 hours go to hospital". This was a wrong information which was also been denied at later stages. On the 9th month, when the child did not move, I went to the Homerton Hospital. Even though I did not have any contractions, or any pain, they broke my water artificially. I urgently had the caesarean section. The baby was born completely purple. He has been given oxygen for 4 days in the hospital. I was told that if we had been late for 2 more hours he could have died.

Later doctors came to tell me that the baby was born with a down syndrome. On the day I mentioned all my previous conversations with my GP regarding my concerns and warnings around the condition. A Turkish interpreter was arranged but I was not listened even if I asked for further advice on complaint procedure.

I went back to my GP and told him that my new born had a down syndrome. He only said "sorry". But later in the court he has denied that he said that. I have not seen that GP ever again. I did not even know I could have changed my GP.

I had another bad experience during my second pregnancy. I had all the tests in Turkey for my second child. Everything was normal. My scan was carried out in the hospital. Because of our previous negative experience, health professionals considered all our requests and answered all our questions this time. Amnio-sythesis was carried out. I had an early scan while I was 3 months pregnant. I had been told that baby was in the wrong place and they had figured this out as a result of the blood tests. They told me that they were going to carry out EPRC to terminate my pregnancy. The following day I put my surgical gown on. While waiting, by a coincidence I came across to an ultrasound specialist and I begged him to check my baby again. He agreed, when he scanned he said the baby was actually in the right place. The operation did not take place; it was cancelled purely by chance. My second child was born with no health condition."

Case 2

- ***Late intervention during pregnancy:*** *undetected position of the baby, ignoring the need for a scan*
- ***Late emergency support during pregnancy :****different intervention in the same emergency situation*
- **Safe Guarding concern**: lack of knowledge /training and accountability of the professionals. DV victims should be able to access information about their rights, services to support them including refuge space they can be accommodated

Everything was normal up until month 7 when the mum started feeling severe abdominal pain. She kept in the hospital for 3 hours. The baby was not moving. The mum's hands and feet were swallowed. It did not feel usual to her but she was told everything was ok every time she was checked.

On the last days of pregnancy, when her contraction started she went to hospital, however, she was told that she was not ready and sent back home. She was experiencing severe pain on her left side. It continued until the morning. She went to the hospital. Her cervix canal was not opened naturally; therefore the water was broken artificially. The baby was not moving. She was vomiting constantly. The staff told her that they needed to wait until the morning, expecting baby to move until then. The health professionals were only checking the baby's heartbeat. No matter the mum told how extreme pain she had and the baby was not moving, no action was taken by the professionals. When the staff shift changed in the morning, her situation handled as an emergency and she was taken to the delivery unit urgently. She went under C-section where the professionals realised that the baby was stuck in one position.

After 8 months of the birth, a bent was noticed in his spinal cord of the child. Later, the child had also gone through operation from his left ear and left testicle. GP told parents that it might have had happened after the month 7 when baby got stuck in the womb. GP claimed that hospital should not have waited for so long before the C-section and scans should have been done at an earlier stage.

She noticed an abnormality with her child's development when he was 6 months old. However diagnose of autism took almost 3 years.

During her pregnancy the mum experience extreme physical and emotional domestic violence, however, she did not disclose it. When the child was 1.5 years old, the mum disclosed her experience of Domestic Violence to a health visitor from Hackney Ark. She was constantly crying. The health visitor visited her again 1 week after with an interpreter. The mum explained all the details. Although it was a safe guarding case the mother was not referred to any service, The only advised given to her was that she should go to the police. The health visitor said the mother had no rights due to No Recourse to Public Funds.

The mother did not go to the police immediately but waited until she couldn't bear with the violence. When the perpetrator husband poured boiled water on his wife, as the physical violence became extreme, she called the police. Afterwards Nia Project got involved and she was provided with all necessary support. If it was not her own instinct, she would have still been in the same vicious circle.

Case 3

- ***Emergency intervention:*** *standards and protocols of intervention should be reviewed for similar emergency situations.*

The mum went to hospital when water broke naturally, but staff at the Homerton Hospital turned them back home and asked them to come back in 2 or 3 days. Next day due to the contractions, they went to hospital again. They were told that they were late and they should not have been sent back before. The contractions were not very often but she was told to push hard to give birth in a hurry. The baby got stuck in the pelvis. It was a very difficult delivery. Baby experienced lack of oxygen. The mum was cut and stitched. Soon after the child was born, parents realised some behavioural issues. Later, when the child was 2 years old, she was diagnosed with autism. The parents still concerns that the baby's disability could be related to things went wrong (late and wrong intervention) during the labor.

Case 4

- ***Late diagnose*** *of down syndrome*
- ***Specialised mental health support is needed*** *during pregnancy when a condition diagnosed with the unborn baby*

At the '3rd month scan' nothing abnormal was detected. At 'the 5th month check', the baby was diagnosed with down syndrome. Due to the late diagnose, the parents were not given choices in time to make informed decision. The child was born with a down syndrome. During the appointments only mother was available. The mother found the staff very respectful and very considerate of her religious beliefs. She added that both parents should have been supported to get involved in appointments and provided with emotional support for accepting the disability.

Case 5

- ***Lack of specialist staff:*** Scan results should be inspected by specialist doctors

The child was born in 2004. When he was 1 y.o., parents were concerning that he had a condition. Health professionals' diagnose (CEREBRAL PALSY) took 2 more years. The family spends most of their time for ongoing appointments in hospital. The referrals take too much time. The process is too slow. The family have concerns about 3/5 month scans during the pregnancy where the condition might have been diagnosed, and also 3/6 month vaccination where he did not feel alright and his behaviour changed. No one gave family an assurance on what side effects / risks of the vaccination.

Due to such unexplained cases, many families are rejecting the necessary vaccination vital for their children's health.

Case 6

- ***Specialist staff needed to make*** early diagnose through tests and scans

"I gave birth to my son in 2007. He was diagnosed with his disability at birth. I have concerns about the labour as it was very difficult. My vagina opened 8cm but I have been told it was not enough therefore they cut it 2 cm more. It was still not enough for the baby to come out and they used vacuum. If I was scanned prior to the labour, they would have realised that my son's head is too big. They should have done C-section instead. He was vacuumed out and there was hypostasis in his brain and he was left without oxygen. Another doctor told me that this condition (LISSENCEPHALY WITH AGENESIS OF CORPUS CALLOSUM) should have been detected during the scans as one side of the brain was physically different than the other side. I believe it is negligence. On top of all this problems, now he is 8 years old and having epileptic fits"

Case 7

- ***Choices to make informed decisions*** *should be given at an earlier stage of the pregnancy*

"I did not have a positive labour experience with my first child who was diagnosed with autism when she is 4,5 years old.

The doctors pushed me to give birth 15 days earlier than the actual due date. Even if I told them that it was early, they did not accept that the intervention date was wrong. Control should be shift to patience as we know our body better. I was not prepared for the birth properly. I was not given choices about the type of birth procedure or type of painkillers that I could choose from.

I was given injection for artificial contraction. Midwifes had to pull the baby as I could not push it. I have concerns about 1 hour struggle with pushing my child. I was bleeding very heavily and therefore removal of my uterus was considered but luckily bleeding was stopped.

The baby pooped during birth and also the cord was around the baby's neck. She was put in oxygen max. She was left without oxygen for a while. Her colour was purple when she was born.

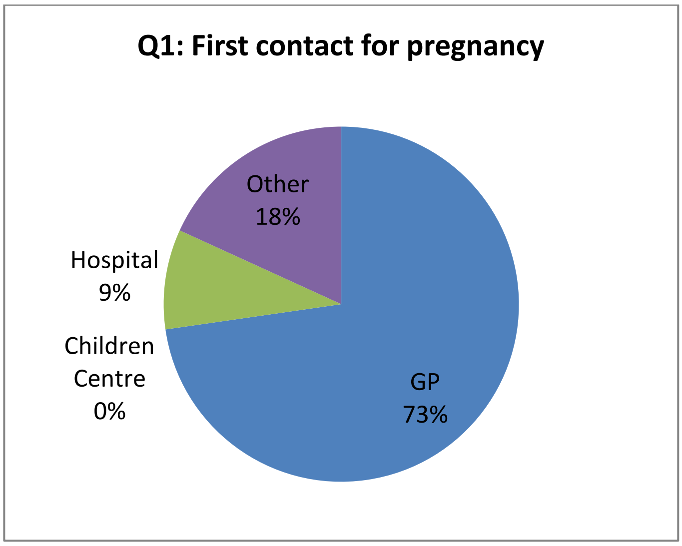
My husband was not engaged in the process. I was experiencing domestic violence. I have been asked about it but I couldn't disclose anything because I was not aware of my rights at the time. The questions asked around domestic violence were part of the standard procedure and yes or no answers were expected. I felt that even if I would have said yes I wouldn't be supported in terms of my rights and my options

About the services related to my child's disability…The doctors only talk with me and meet me but what I really would like them to do is to work with my daughter directly. I explain her issues and her behaviour. Then the doctors make a plan for me to follow. Whereas I would like them to come to my home and observe my child, try to communicate with her and have an independent view, see the issues from my daughter's point of view, and assess her as a unique individual. We need practical support not on paper"

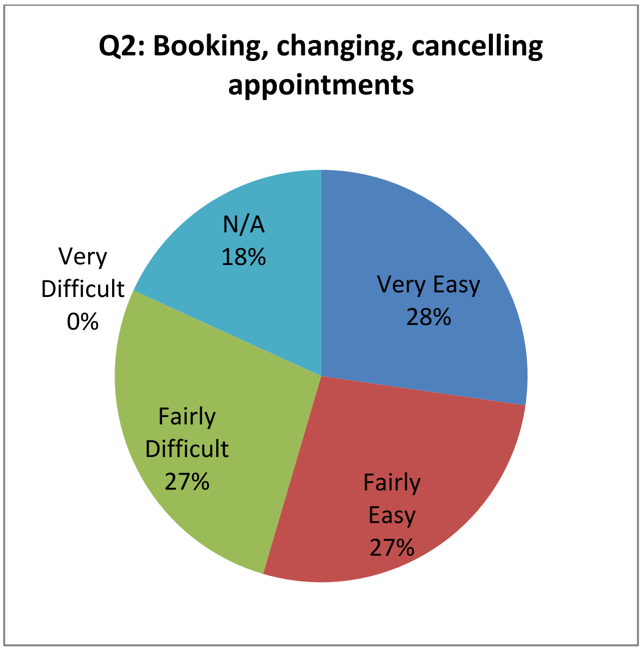
Qualitative Results

Antenatal Care

Q1: 8 of the parents/carers stated their first contact for pregnancy was their GPs.
The 2 of the parents have given birth outside of UK therefore stated the first contact for pregnancy as the 'other'.



Q2: Parents/carers had different experiences about how they have found booking, changing, cancelling their antenatal appointments nevertheless none of the respondents found the process 'very difficult'.

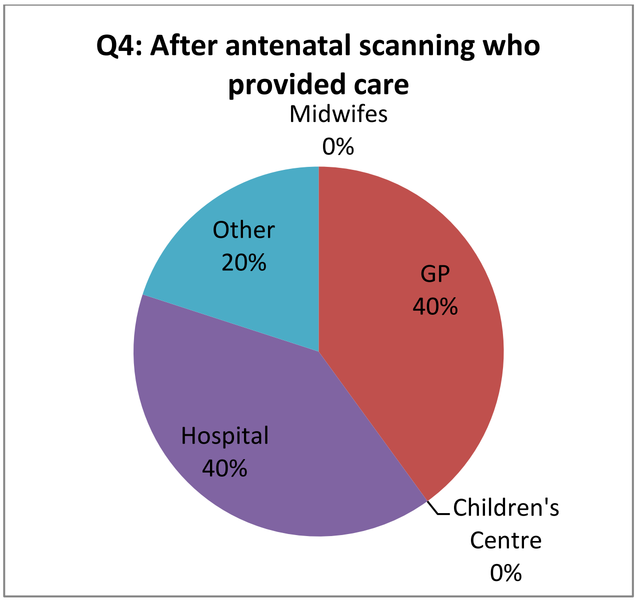


Q3- All parents/carers except from 3 had their antenatal routine screening and scanning in Homerton Hospital.

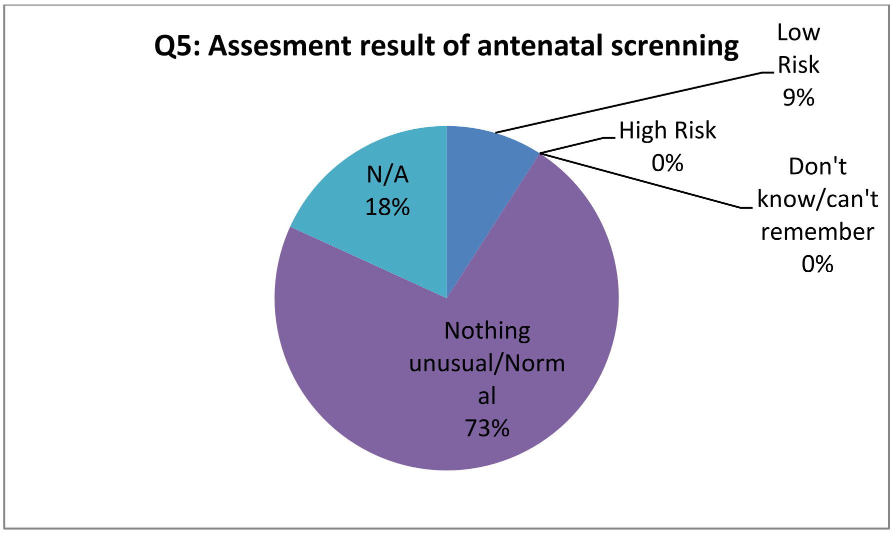
1 parents/carers out of 3 had their antenatal routine screening and scanning in a private clinic in Turkey, other 2 had it in a hospital in Turkey. Parents/carers have stated that they would neither be able to effort private clinics in the UK nor be able to effort if there would be any charges applied in NHS services.

Q4: 4 parents/carers stated they has the care following antenatal scanning and screening in Homerton Hospital and other 4 stated they had it in their local GPs.

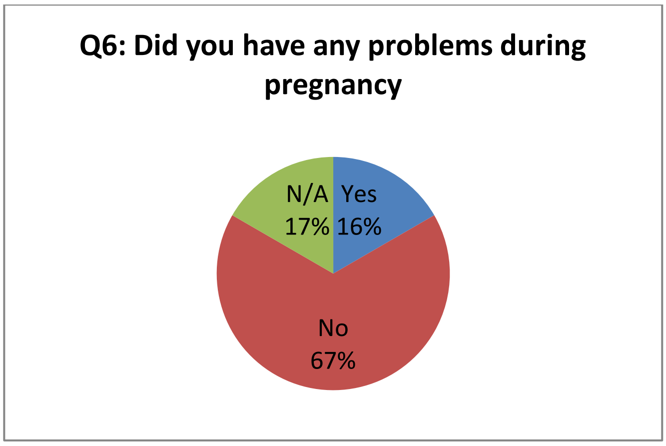
The 'other' indicates the babies who were born in Turkey.



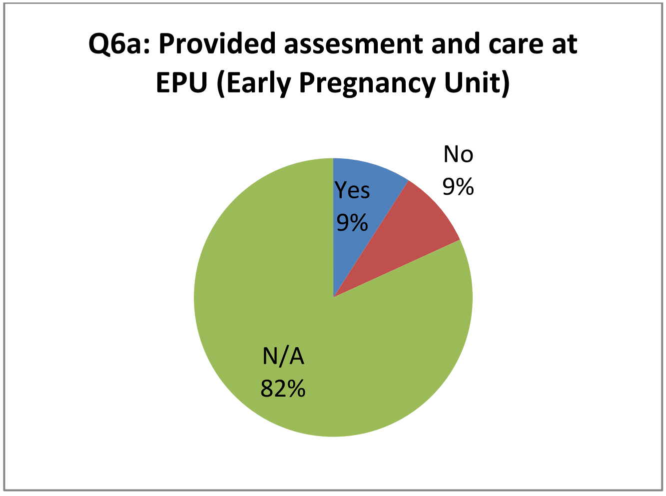
Q5: None of the parents/carers have been diagnosed with any kind of risk during their antenatal screening



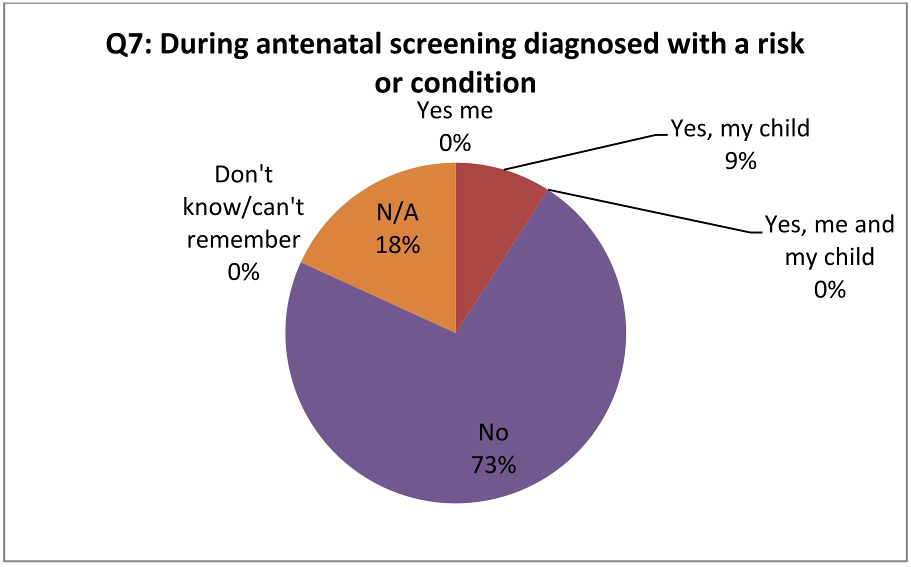
Q6: 2 parents/carers have stated that they had problems during the early pregnancy. 1 of the parents of these 2 believed that the problems she went through were due to negligence by her GP which later turned into a legal case.



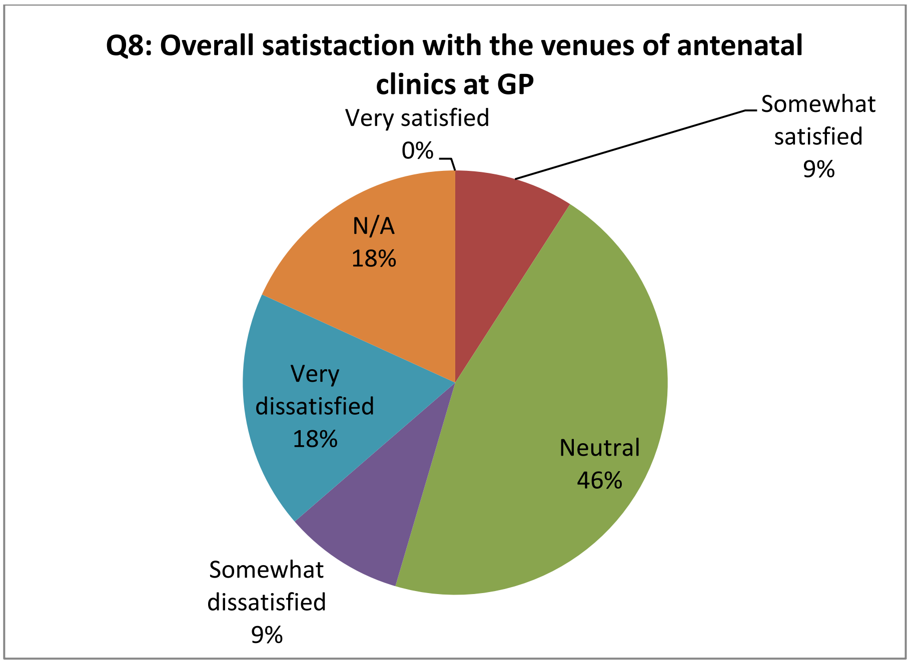
Q6a: None of the parents except from 1 have been provided assessment and care at EPU (Early Pregnancy Unit).



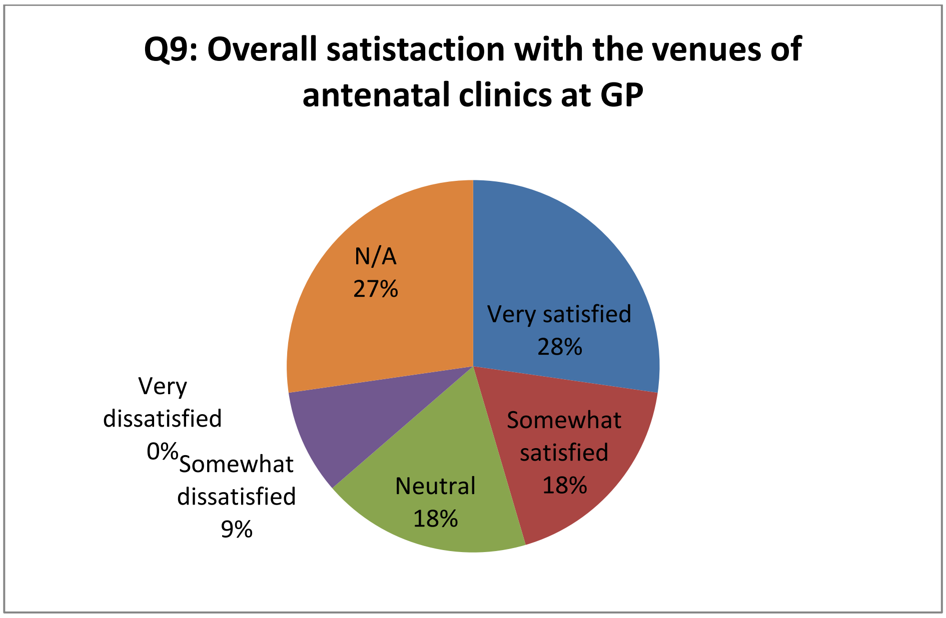
Q7: None of the parents/carers except from 1 have been diagnosed with a risk or condition during their pregnancy. One of the parents/carers who has a child with Down syndrome believed that the condition should have been diagnosed during antenatal screening. One of the other parents/carers was diagnosed with chromosomal incompatibility when the child was 9 years old.



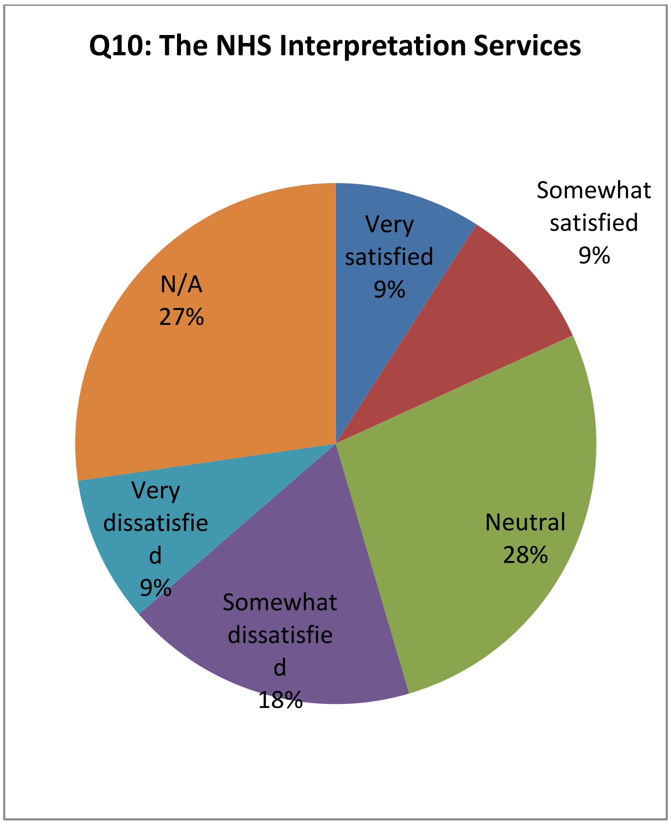
Q8: 5 of the parents were neutral, 2 of the parents were very dissatisfied, 1 of the parents was somewhat dissatisfied and 1 of the parents/carers was satisfied with the venues of antenatal clinics at the hospital.

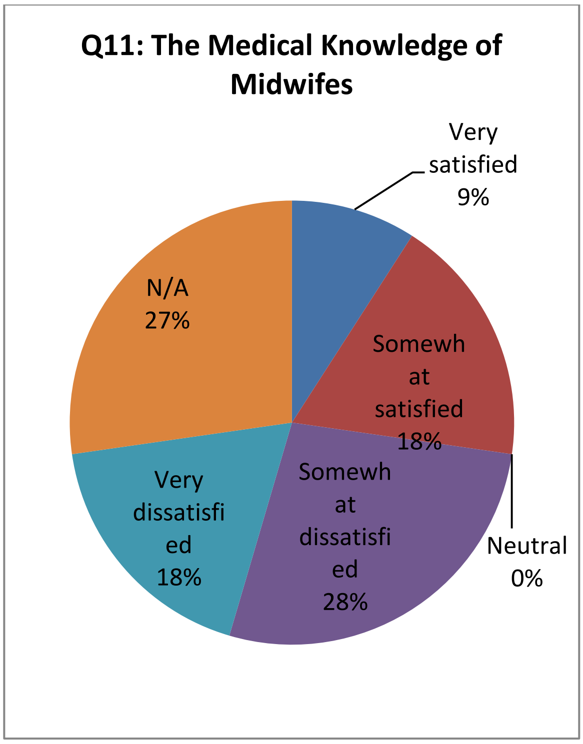


Q9: 2 of the parents were neutral, 3 of the parents were very satisfied, 1 of the parents were somewhat dissatisfied and 3 of the parents/carers were very satisfied with the venues of antenatal clinics at the GPs.

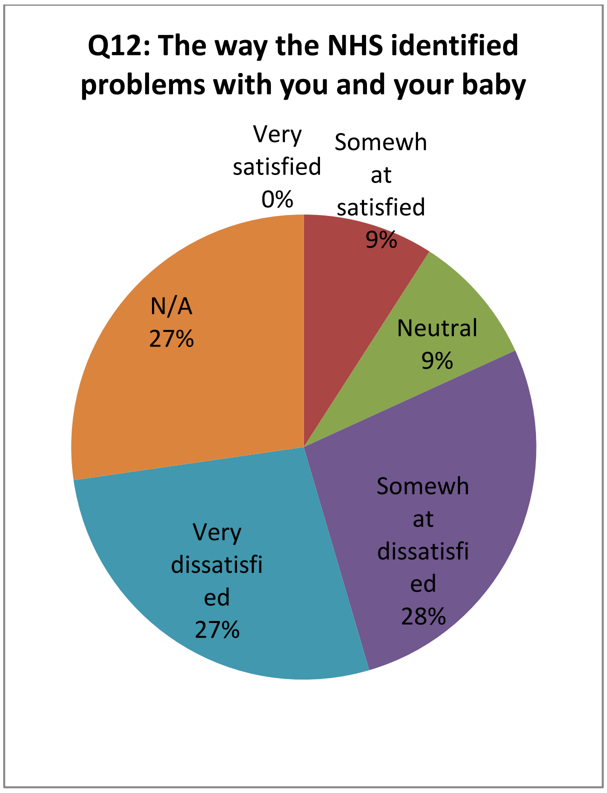


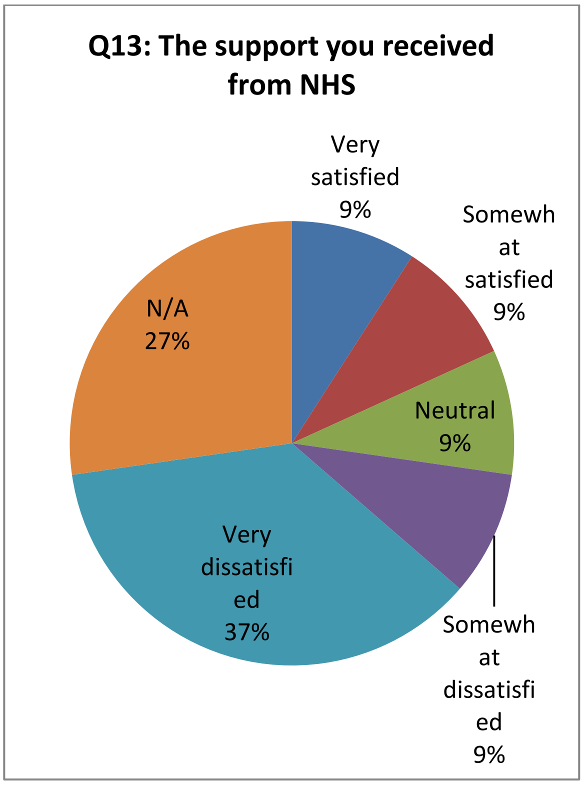
Q10: Parents/carers often stated that they believe training for working with families, and/or advice and guidance.





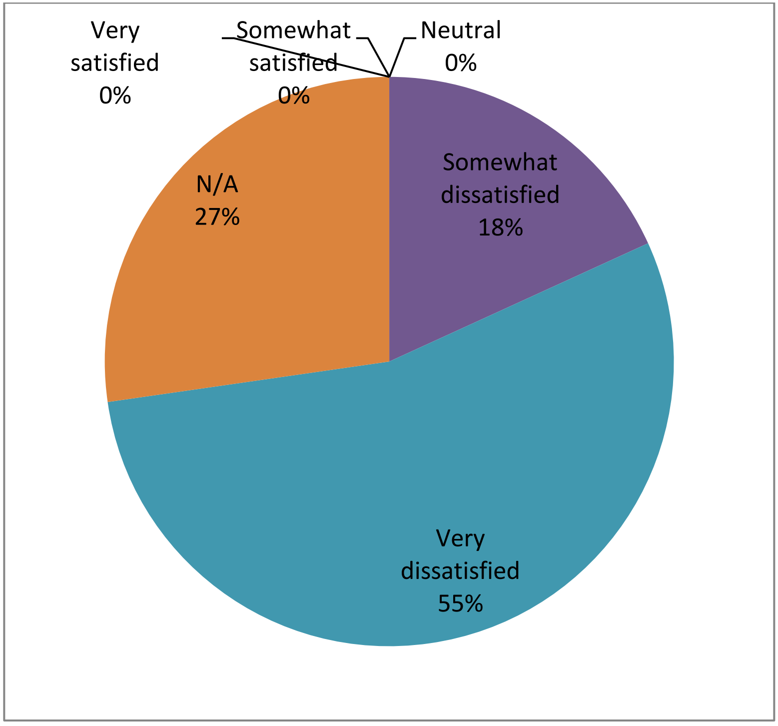
Q12: Diagnosing the condition was very late. 3 appointments for tests took 1 year.



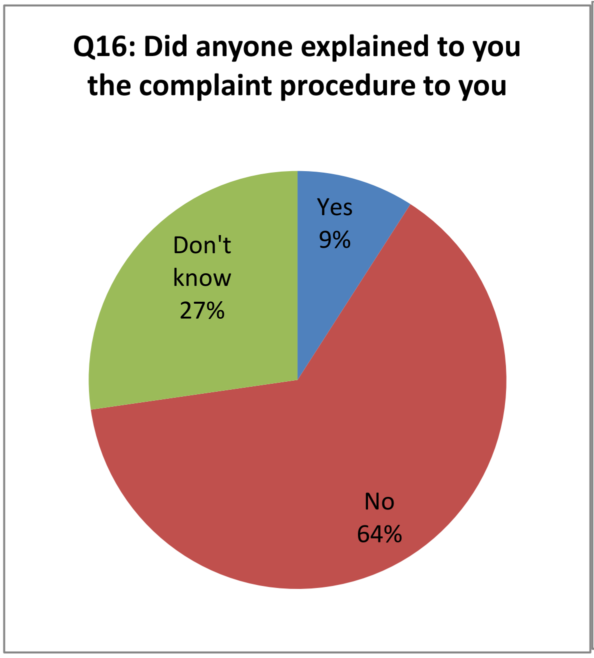


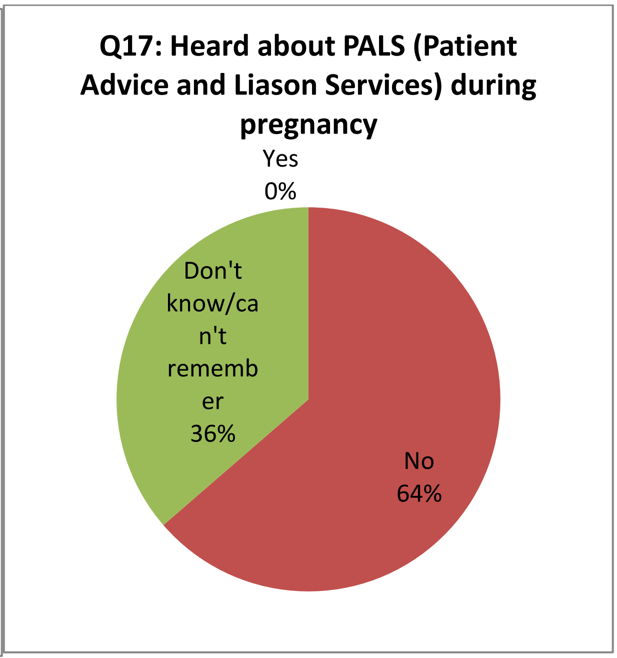
Q14: None of the mothers were satisfied with the involvement of the fathers in the process before and after the birth of the disabled child. The mothers have stated that there should be mechanisms in place to assess issues such as domestic violence in the family as well as support and encouragement to involve the fathers in the process of child care.

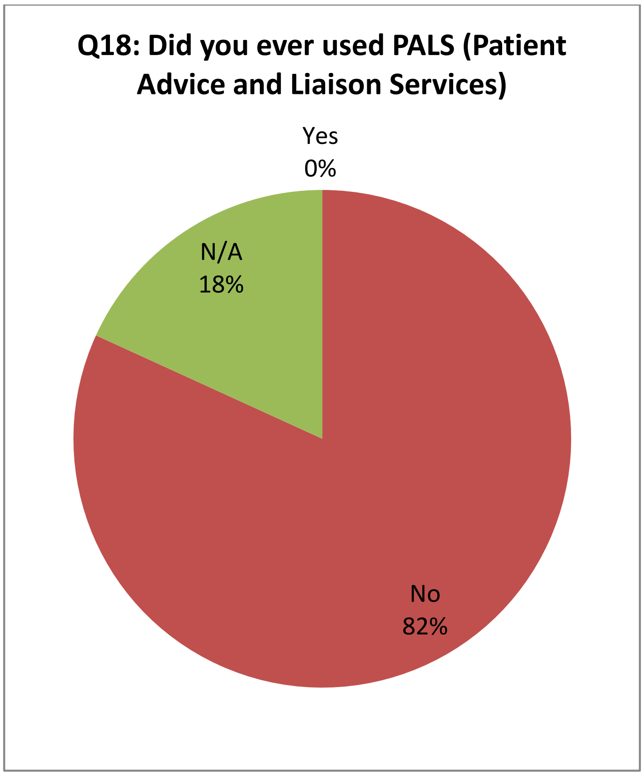
Q14: The support your partner received to stay involved in the process



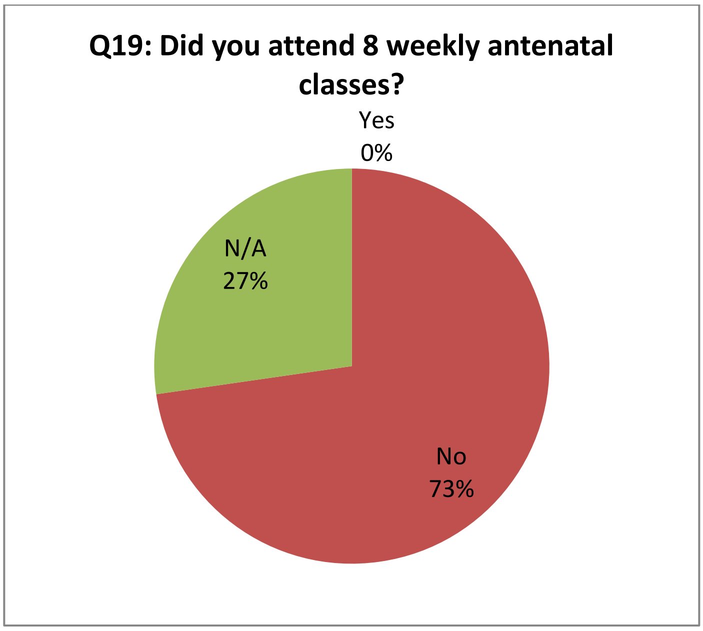
Q15, Q16, Q17, Q18: Only few of the parents/carers indicated satisfaction with the way NHS provided information to help them make informed choices and decisions as well as knowledge about the complaint procedure and PALS (Patient Advice and Liason Services). None of the parents/carers have used the PALS (Patient Advice and Liason Services). Parents/carers have stated that language barriers and lack of services in their mother tongue have been the main cause of the lack of information


Q16: Did anyone explained to you the complaint procedure to you


Q17: Heard about PALS (Patient Advice and Liason Services) during pregnancy

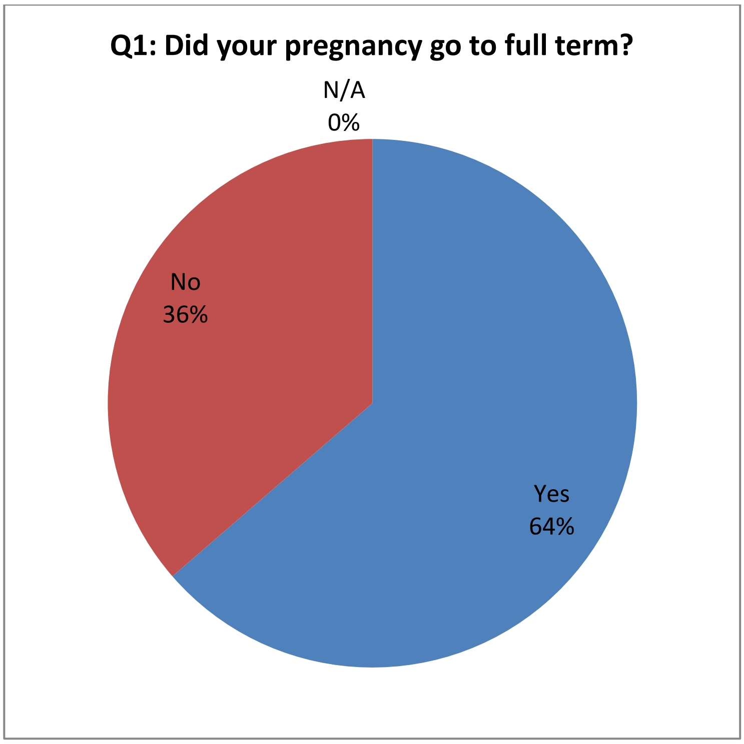


Q19: None of the parents/carers have attended the antenatal classes due to not knowing that this service has existed. Majority of the parents/carers stated that they would not be able to effort to pay for the classes if there would be charge. Some stated if they are to pay for the sessions, maximum they would have paid would be £5.

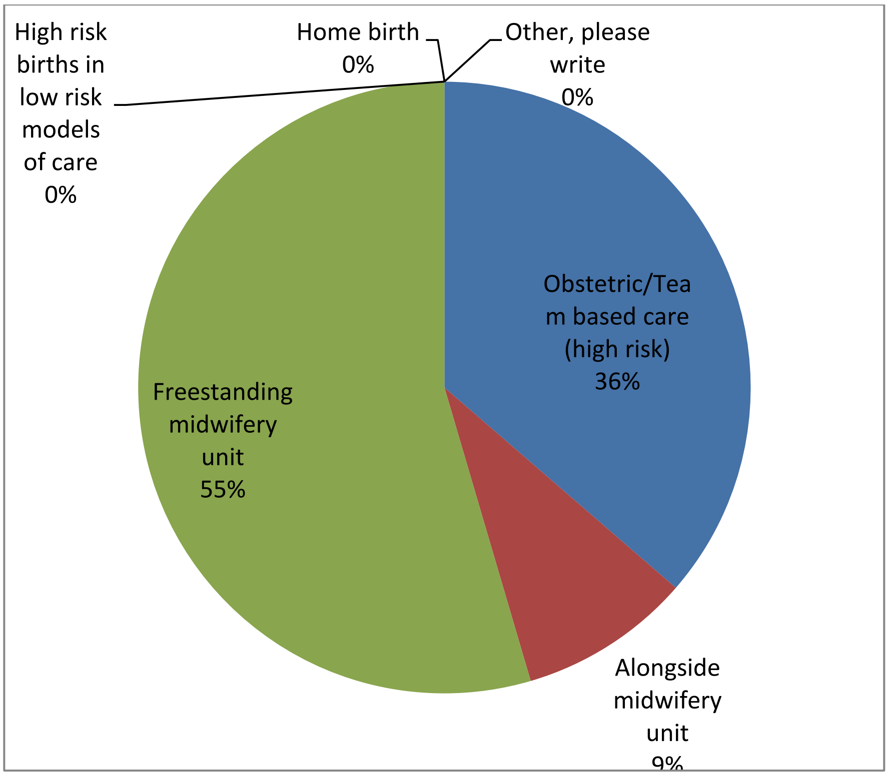


Intrapartum Care

Q1: 7 parents/carers have said ‘Yes’ and 4 parents said ‘No’ to Q1.

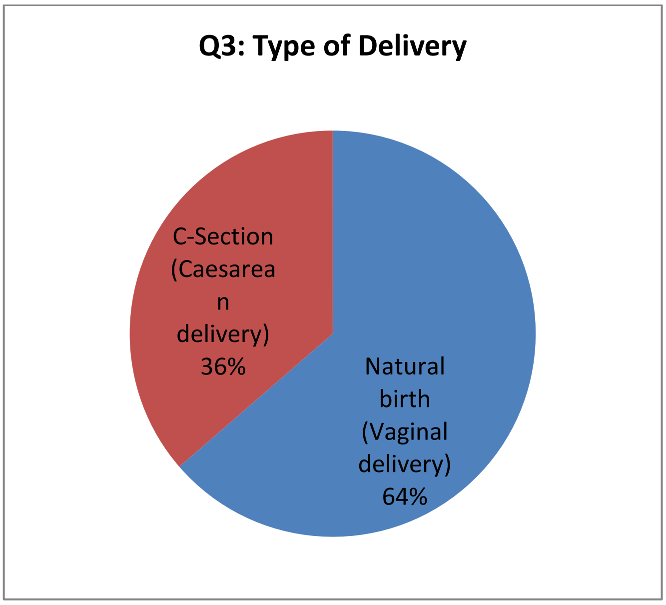


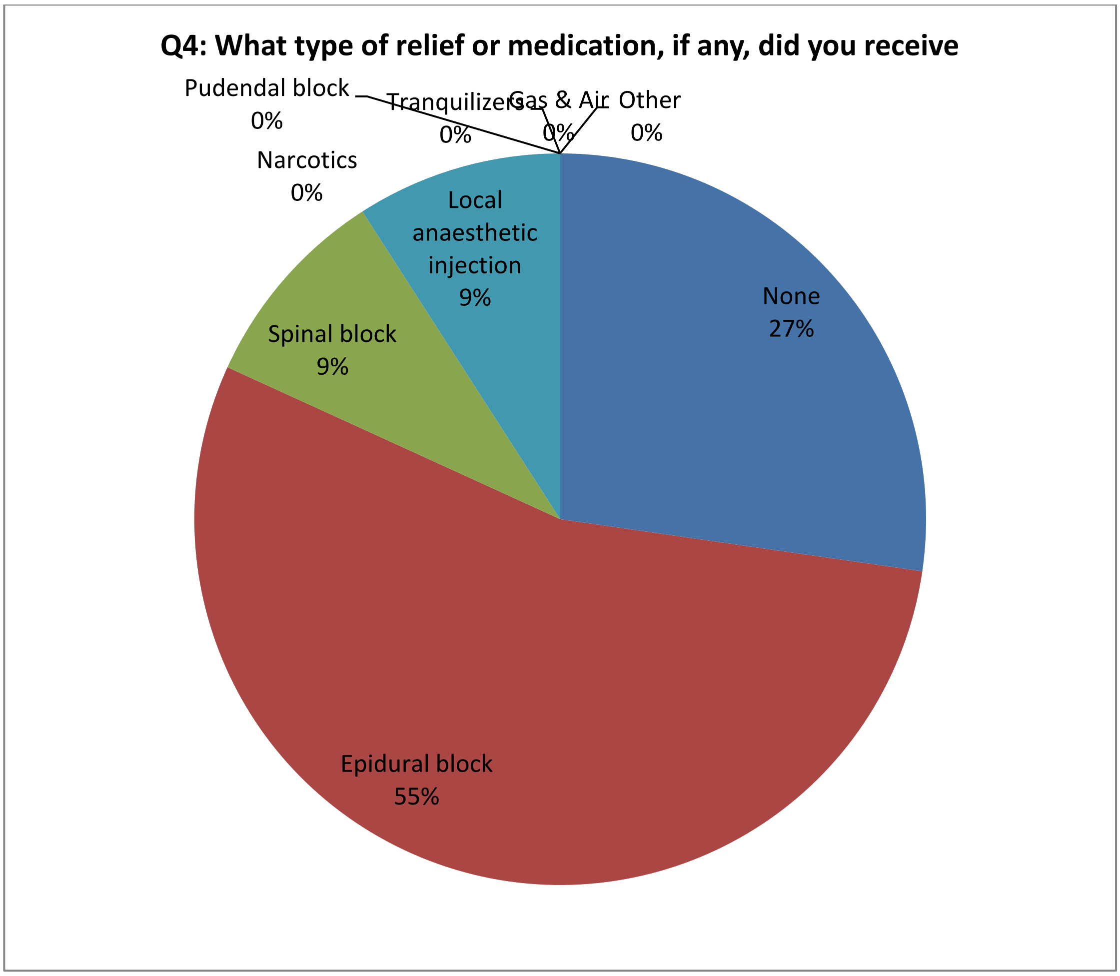
Q2: Which unit provided you with care during labour?

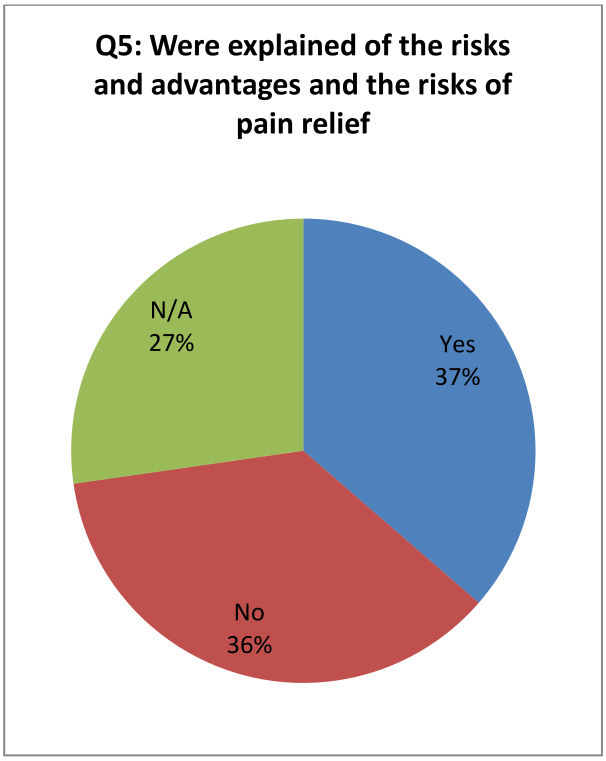


Q2: Number of Parents/carers

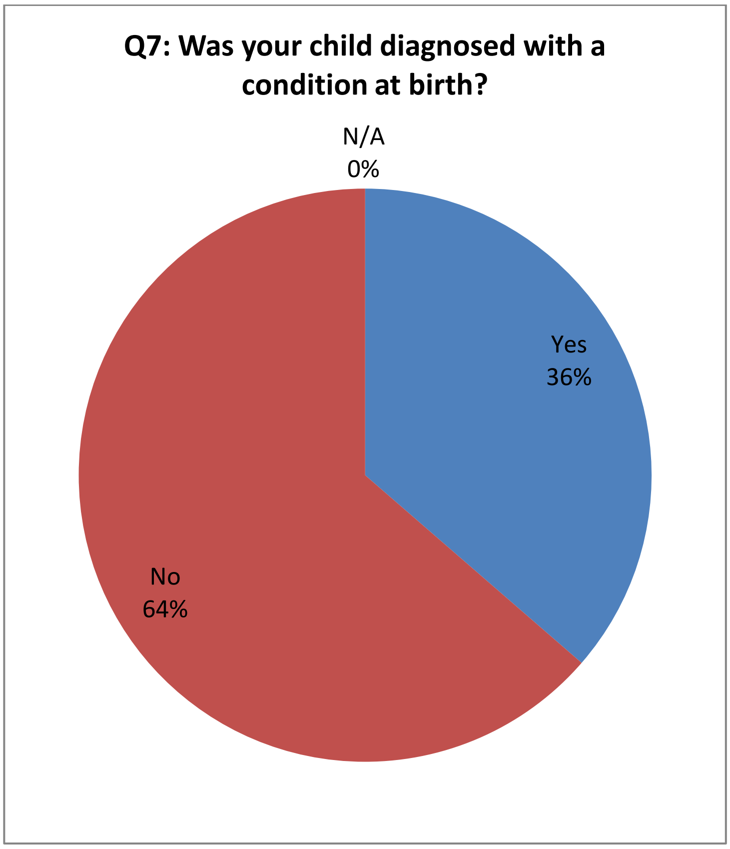
Obstetric/Team based care (high risk)	4
Alongside midwifery unit	1
Freestanding midwifery unit	6
Home birth	0
High risk births in low risk models of care	0
Other	0







Q7: A comment box has been included to the question. Following are the comments of the parents/carers in regards to the questions.



S.U. : *"The child was born with a down syndrome although he was not diagnosed during the pregnancy".*

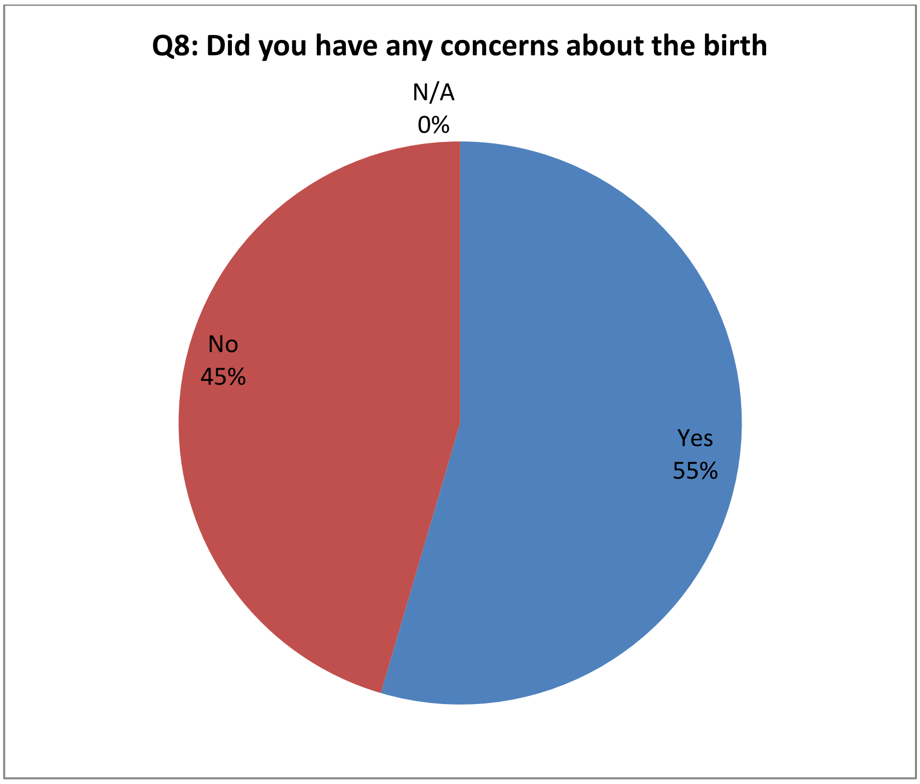
D.G. : *"The baby pooped during birth and also the cord was around the baby's neck. She was put in oxygen max. She was left without oxygen for a while. Her colour was purple when she was born."*

D.T. : *"They could not understand what it was but I was told that he is disabled. MRA was taken after the birth when doctors see the hypostasis at his head which should have been diagnosed at 3-5 months scanned."*

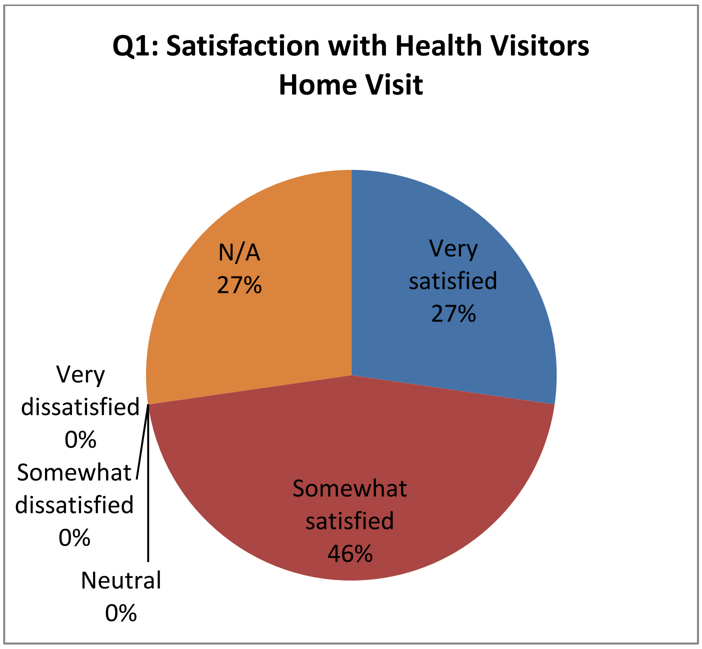
G.B.: *"At birth the child was born completely purple, they thought he was dead but then he came back to normal."*

S.E. : *"The condition was not named, but there was a possibility of partial impairment at baby's ear and eye as told by the staff."*

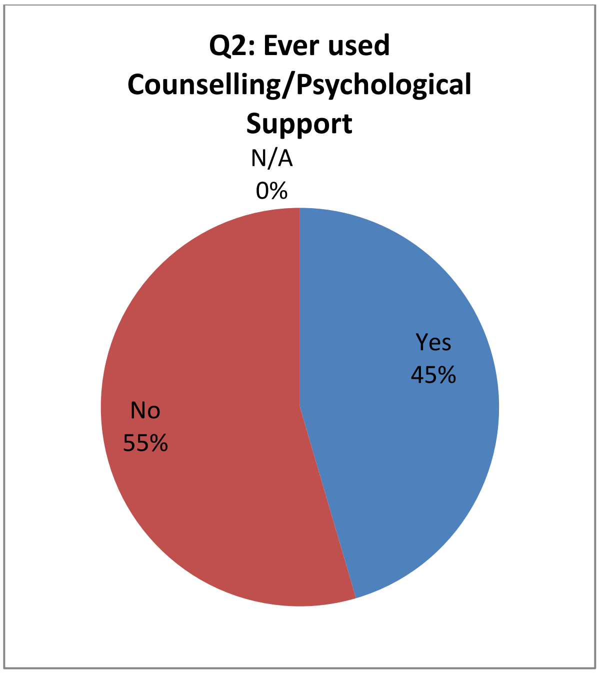
S.S. : *"The baby pooped during birth and baby's water bag did not burst. They burst it artificially. As a result when baby was born his head was scratched when he was born."*

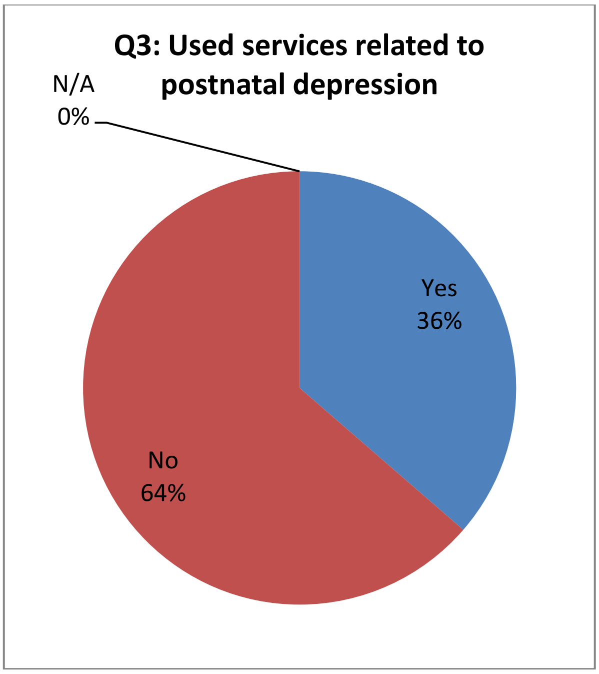


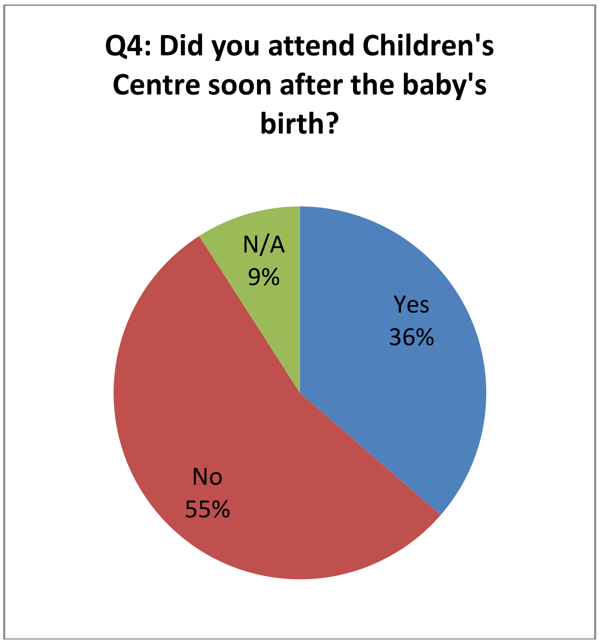
Post Natal Care & Disability Service

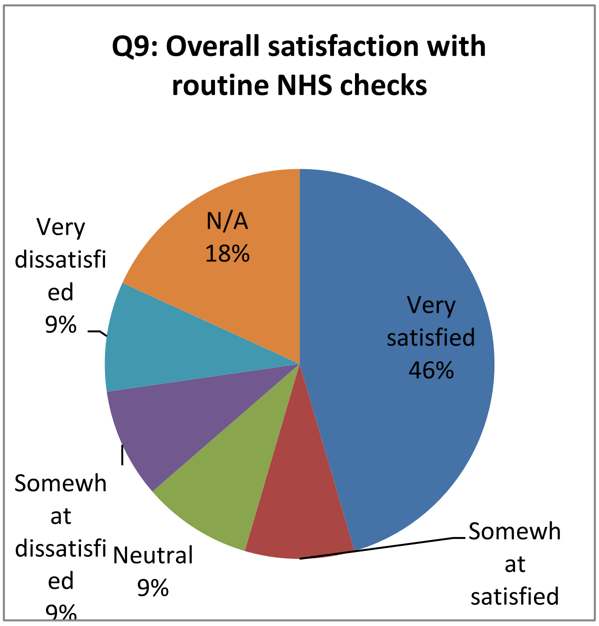


Q2, Q3: Parents/carers who answered ‘No’ to question 2 and question 3 have stated that they were not aware of any counselling/psychological services. All parents/carers who answered ‘No’ to question 2 and question 3 except from 1 have stated that they would have liked to be supported by psychological/counselling services if they would have been informed.

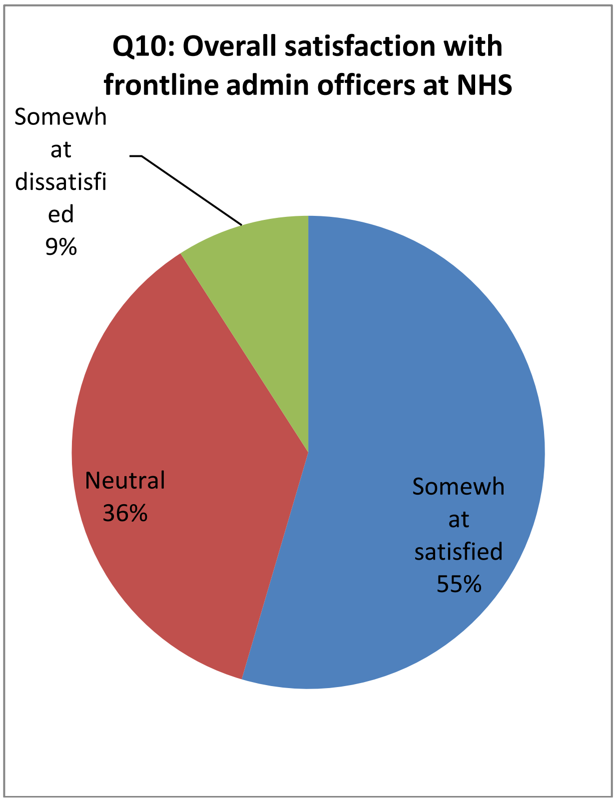


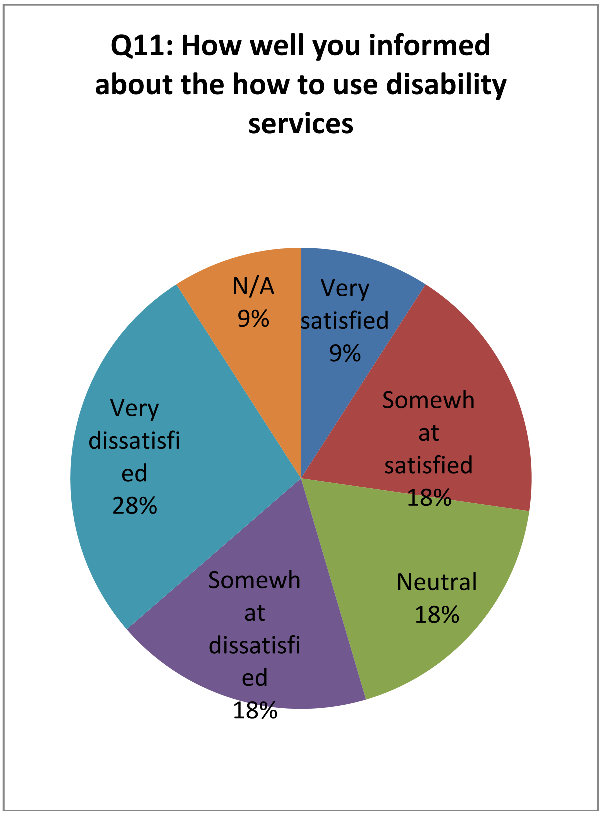


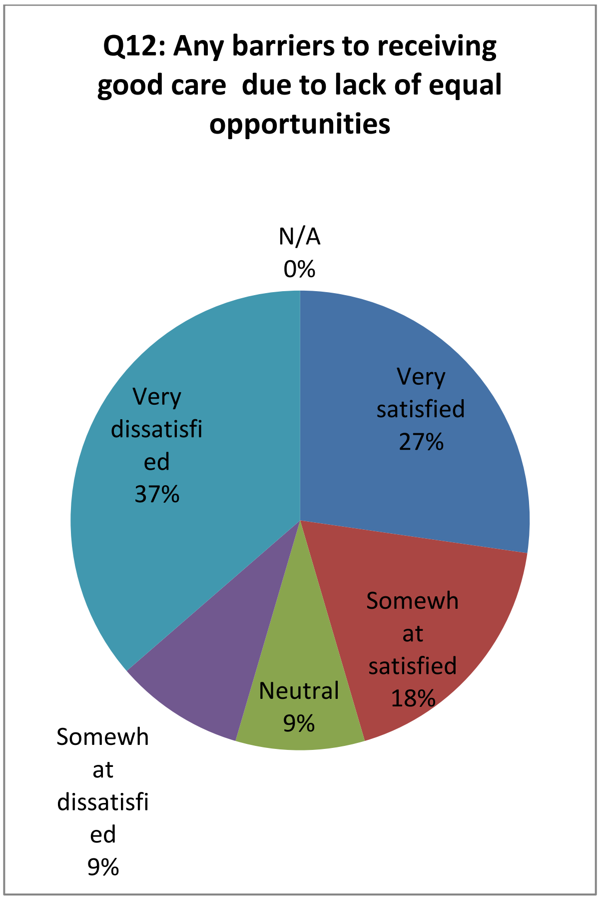


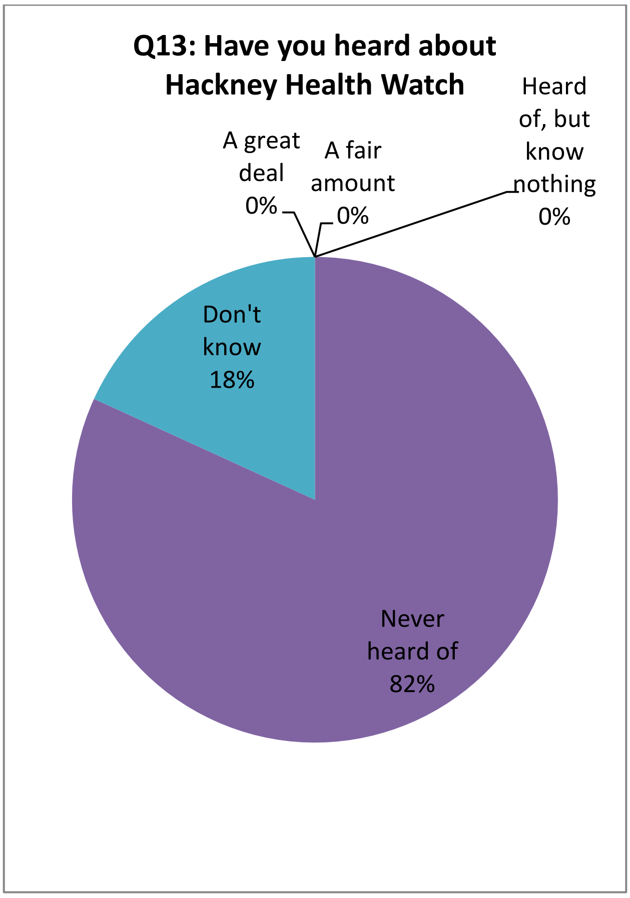


Initials parents/carers	**Q5. When did you realise that your child had a condition?**	**06. When did the professionals diagnose your child with a condition?**
H.G	*1.5 years old*	3 years old
D.T	Since he was a baby	5 years old
G.B	Since he was a baby	5 years old
G.B (second child)	3 years old	5 years old
A.K.	5 months through the pregnancy	5 months through the pregnancy
D.G.	6 months old	4,5 years old
S.B.	At birth	At birth
S.D.	2 years old (as he was not yet speaking)	3,5 years old.
S.S.	2 months	8,5 months
S.U.	3 month pregnant (diagnosed in Turkey)	At birth (diagnosed in UK)
F.H.	1 years old	3 years old
S.E.	6 months old	8 months old


Q10: Overall satisfaction with frontline admin officers at NHS


Q11: How well you informed about the how to use disability services


Q12: Any barriers to receiving good care due to lack of equal opportunities


Q13: Have you heard about Hackney Health Watch

Quotations/suggestions from parents

1. Antenatal

What worked well in antenatal services?

- Appointments were very regular
- I am quite happy with their direct talk. They are open-minded about different issues and have given me options about how they can support me.
- They were very respectful, very considerate of my religious beliefs. They did not impose ERPC, I have been given options.
- Attitude of the staff was very positive
- Appointments were kept at the promised time. The waiting time was not long.
- Test and routine appointments were very regular
- Being directed to a midwife was great
- Good care and regular services.
- Scan professionals were very attentive

What changes, if any, would you like to see in antenatal services?

Early intervention through patient centred approach

- Specialist professionals need to carry out scans and blood tests in order to track the condition at an early stage. They play crucial role in the process. Their mistake devastates lives. Blood tests should be repeated if concerns arise.
- GPs and midwifes should be more approachable, more experienced, and promote professional attitude.
- One health professional (doctor/midwife) should be designated for each family and take the responsibility of a key worker from day 1 of the pregnancy to couple of weeks after the birth. As currently too many different staff deals with each family.

Translation services and support services in mother tongue

- The interpreters should be present at all times especially during emergencies.

Not just when there is a booked appointment.

- Some interpreters have attitude issues; therefore they need to take training for working with families, and/or advice and guidance.

- ‘I needed interpretation desperately. But interpreters were not qualified /specialised. Most of them are not approachable. They need to get training for better communication skills.

- ‘We live in a close community. The Turkish interpreter who was available in my appointment where I learnt that I am pregnant, later told my mother in law that I was pregnant when she was interpreting for her in another appointment. It was an unplanned pregnancy and I did not want anyone to know about it. This is a breach of confidentiality and happens very often’

- For the new comers to this country (with language barriers and people who do not know how the system works) there should be more support to inform and direct them to the right services.

- I took all the leaflets and read them using dictionary. It could have been very useful If there would be some leaflets written in Turkish.

- Extra support needs to be provided for newly arrived immigrants.

Culturally sensitive and accessible antenatal sessions

- I didn’t know about antenatal services. Antenatal classes should be available for everyone and promoted and made accessible to wider community

- Antenatal classes should be compulsory for everyone with interpretation for provide access to everyone

Engagement of partners

My husband was not engaged in the process. I was experiencing domestic violence. I have been asked about it but I couldn’t disclose anything because I was not aware of my rights at the time. The questions asked around domestic violence were part of the standard procedure and yes or no answers were expected. I felt that even if I would have said yes I wouldn’t be supported in terms of my rights and my options.

Specialist mental health support

- I wish we had more support when we realised that we were going to have a disabled child. We should have been provided counselling services to help us with the acceptance of the situation.

- The information about my child's special situation was efficient but it was just about the physical support. I wasn't given any emotional support.

- Mental health support for DV victims to increase their self esteem

2. Intrapartum

What worked well in intrapartum care?

- I have been informed really well about how to care about the baby, how to wash the baby. We have practiced it together, and they were keen to make sure I know how to do the right thing.
- I felt very safe under the inspection of the doctors.
- Attitude of the staff (doctors) were very positive
- Their care for me and my baby was very good.
- Care after the birth was really good
- Care for my baby while I was there was very helpful
- Breastfeeding support was very informative
- Midwifes were caring for and helping both my child and me.
- Before labour, a nurse and a doctor came and explained the procedure, giving them assurance which was very comforting. It would be even better if this consultation took place during antenatal sessions.
- Caring for the new-born (feeding, reliving baby's gas, lying him next to the mum) during the hospital stay was very helpful
- Nurses caring for the mum, bathing her was very supportive

What changes, if any, would you like to see in intrapartum services?

Qualified staff

- Health professionals with different specialisms should be in charge. This gives patients more assurance (that is what happened to me with my second birth at UCL hospital)

- At least 2 health specialists should be present at birth. Complications might. We would feel safer if there are two members of staff available. Only one staff is not enough and efficient. If they are not in a good mood or having personal problems on the day, this may impact on the process of birth.

- One staff designated to the family from day one could be present at the labour, providing advocacy and following up patient's rights.

- Doctors should be present at birth

- The staff should take training on working with families. The mum says soon after the delivery, a nurse shouted at her when she asked for practical support.

Specialist mental health support

- When the baby's condition was disclosed to the parents, I think it should be done with more care. It was too direct, I was really shocked.
- Also my partner was never assessed whether he is need of emotional support
- There should be a service before discharging parents to prepare them emotionally and give information about where they can seek help.
- The hospital should provide emotional and practical support to both parents. It is not only mother's responsibility.
- There was only one midwife. There should be a specialised doctor.
- Specialist doctor should carry out the birth

Patient centred approach

- Each case should be taken as unique. For example in some cases the mother may need extra support after birth due to her stitches and losing too much blood, but the care given was standard not patient centred.
- They made me lie down on the bed and forced me to open my legs. They did not ask my choice of birthing position.

The rooms, visiting hours, attendants

- When the contractions started, the parents went to Homerton Hospital. The staff turned them back saying it was early. There should be space for expecting mums who feel safer in the hospital.
- At the first night of the birth, one guest should be able to stay over the night with the mum and the new born baby.
- Someone should be allowed to stay with me. I did not get practical help when I needed. They just do what they have to do nothing more than necessary but everyone has different needs.

- I was sharing the room with other 8/9 mums and new born. Visitors coming and going was very tiring. It was very loud and disturbing.

- Labour rooms should be bigger and more comfortable

- Staying alone overnight was very difficult. Night staff could only deal with the baby but if someone deals with me it wouldn't be a very difficult experience for me as I was very tired.

- C-section and natural birth mums should be allocated to separate rooms

- Ideally each family should have their own room

- Visiting hours should be shorter

- Everyone should be provided their own private room

- One should be allowed to stay with the mum over the night

3. Post Natal & Disability

What worked well in Post Natal Care & Disability Services?

- I think the staff at Hackney Ark is doing a very good job.
- The services are free and we have access to all of them, which is great
- Nursery is provided.
- I am very happy with Hackney Ark, including the receptionist, staff and the service provision
- Shortbreaks service is working very well.
- Hackney Ark is easy to access by means of location and interpretation.
- The specialist doctors are very good.
- Physiotherapy was very beneficial.
- The support sessions were on weekly basis and improved my child's walking. They have directed and informed me very well.
- Doctors at Hackney Ark are very well. They are very approachable and understanding.
- Reminder services for appointments are great.
- Housing adaptation services for disability was great. It made our life much easier.
- Arranging interpretation was easier.
- Parent partnership is a very helpful service
- Hackney Ark provides very efficient interpretation service
- Specialised hospitals are very good especially for surgeries.
- The staff at Hackney Ark are very approachable

What changes, if any, would you like to see in Post Natal Care & Disability Services?

Quality standards

- I would improve the waiting time (we wait really long in hospitals and Gps)
- Transportation services should be improved.
- I would like ambulance services to be improved.
- ‘When new physical support equipment tried on and if it hurts, we have to wait for the next appointment, since then my son suffers. There should be emergency appointment system to comfort children with the difficulty and pain the children experience.
- ‘Always the cheapest option as a treatment is being implemented. For example, they have applied Botox to my son’s foot, when it did not work doctors carried out a surgical operation. They shouldn’t try twice. We feel like we are the guinea pig’

Early diagnose

- Diagnose process should be faster. Appointments shouldn’t take years
- Investment should be done on researches and studies for earlier diagnose
- Earlier made the diagnose leads earlier engagement to support services.

Qualified Staff

- I believe that the health visitors need further training about disability to direct/ signpost families more effectively. I would like to be informed well and access them at earlier stages.
- After diagnose, the child should be provided with 1 to 1support. The parents were often told to take the child to a nursery/play groups. However, there usually is not a specialist health/education professional to deal them on a 1 o 1 basis.
- The doctors only talk with me and meet me but what I really would like them to do is to work with my daughter. I explain her issues and her behaviour. Then the doctors make a plan for me to follow. Whereas I would like them to come to my home and observe my child, try to communicate with her and have an independent view, see the issues from my daughter’s point of view. I do not believe that the issues can be resolved by only explaining issues to me. I need practical support not just information on paper.
- ‘Life is already very difficult for carers, so I would try to make it easier for them. Instead of medication or equipment support, I would focus on the actual treatment. We have

been running around from one appointment to another for the check-ups and assessment. Treatment is always being delayed, so are the surgical operations.

- ‘I wish the same physiotherapist can work with us for a long period of time. The physiotherapy staff changes very often. We really would like to be able to choose them, as our first physiotherapist were giving us assurance, practical support and options, but some of them are not approachable at all’

Support services

- Housing officers were not helpful. No one helped about our housing issues, we have struggled ourselves. Carers needs to be put in priority

- No information was given for transition services I feel like I am lost. This information needs to be given beforehand.

Culturally sensitive approach

- Our culture gives the role to women to do all the work for the family. Culturally sensitive approach should be developed in NHS. If professionals are aware of these cultural barriers, they can engage partners and this will lead sharing the responsibility of caring for disabled children and helping mothers physically and emotionally.

- I still cannot accept that I need counselling as it is a taboo in our culture. It was offered to me at the beginning. I still have difficulty to act to seek help although I know that I need it.

- Families unfortunately expect a lot from the external services. I believe that we can do a lot as carers of autistic children. But often families are lost and mostly in denial of the situation.

Summary of Recommendations

- Antenatal sessions should be compulsory and delivered in partnership with culturally sensitive community organisations to increase access and support a ‘patient care approach’ where each individual case is taken as ‘unique’ rather than ‘standard’.
- Partners should be encouraged / requested to engage and attend to antenatal appointments for pregnant woman, and disability services appointments for children.
- All the frontline health staff need to have Domestic Violence awareness training. They should provide information about DV support available to every single pregnant woman regardless of their needs assessed through standard ‘ticking the box’ procedure.
- Interpreters should be available in emergency situations.
- Interpretation services’ managers should review their confidentiality policy and make sure staff complies with it.
- Information about complaint procedures and services like PALS should be introduced to everyone at their first contact to NHS, for example at the registration to GP.
- Provision of disability services information in mother tongue will support minority groups for their earlier engagement and therefore early intervention.
- Antenatal screening centres should be given point base ranking according to their accuracy. Scan results must be saved for future investigations and accuracy performance of the centre for the diagnosis afterbirth
- Carer parents should be provided with therapeutic support around acceptance of their child’s disability, and their changing roles and responsibilities as carers, as soon as they learnt about it. This will prevent family breakdowns and help parents with changing the perception of disability they learnt through social constructions.
- Hackney Ark should keep up the good practice with its disability services!

Conclusion

During the discussions with carer parents, common concerns such as medical negligence and late diagnosis were raised often. There have also been discussions on how to overcome barriers to accessing information and services focusing prevention and early intervention.

Carers would like to see a patient centred system where they would be provided with expert advice and guidance and given choices to make informed decision. According to them, culturally sensitive approach will improve the positive impacts and outcomes of the health services. A holistic provision developed within this context in order to increase access and engagement, early intervention (to safe guarding and domestic violence concerns), and prevention of family breakdowns, could be achieved especially through antenatal classes and mental health services.

It was also expressed by parents/carers, never before they had the opportunity to opinion and concerns on that level, that the research process has been an empowering experience for them.

During our 3 year work with Turkish speaking carers, and this research project, we as Minik Kardes staff, also had numerous discussions around ‘social construction of disability’ to consider dominant norms and rules within this specific community, and its impact on carers affecting their parenting skills, and also on professionals affecting their service provision. This led us to develop a better reflexivity within our organisation, and direct us to support mostly user led and therefore empowering formations.

This study is the first part of two researches. Second research will be examine ‘antenatal care’ in detail to develop a culturally sensitive approach to design and delivery of the provision.