

“A Silent Problem”

Perinatal Mental Health in Oxfordshire

Report by the Oxfordshire 1001 Critical Days Coalition.
Report written by Adrian Sell (Chair) Kathy Peto and other
members of the group.

A Healthwatch Oxfordshire Project Fund Report
November 2016



Executive Summary	P3
Who We Are	P4
What We Did	P5
What We Found - the online survey	P6-8
The Service or support that would have been good to have The Service or support that would have been good to have	
What We Found - in depth interviews	P10
Conclusions	P11
Recommendations for local commissioners and providers	P12
Appendix A: 1001 Critical Days Questionnaire responses	PP14-17
Appendix B: Perinatal experiences - semi structured interviews	P18

Executive Summary

The Oxfordshire 1001 Critical Days group was set up in March 2015. It is a coalition of local agencies working with young children and their families in both the voluntary and statutory sectors. Building on the momentum of the National 1001 days campaign at that time, our aim was to increase the profile within Oxfordshire of the first 1001 critical days of a child's life and to raise awareness of the ways in which services for parents and very young children at this crucial period could work most effectively together. We wanted to hear parents' views about their experience of perinatal (i.e. the time leading up to birth, birth itself and the post-natal period) services and support, in order to gain a deeper and wider understanding about what was working well and what could be improved.

We used an online survey and received 36 responses. The survey was then followed up with four semi-structured interviews. The group understood that we would be inviting responses in a context of shrinking budgets, but also at a time when there is both a need and a widespread desire for services to be as joined up as possible. We hope therefore that the findings and voices from the survey and interviews we conducted will be heard at a time when, though resources are tight, there are opportunities for change.

Responses to the survey and follow up interviews identified many positive features of support received, and appreciation, often glowing, was expressed for health visitors, midwives, children's centres, breastfeeding support services, Infant-Parent Perinatal Service, Oxford Parent Infant Project (OXPIP) and others, and particularly for individuals within those services.

Common themes also emerged about the patchiness and inconsistency of support and about primary, secondary and other community care services often not linking up and sharing information effectively. Many parents said that they'd had to repeat their stories many times to different professionals, or to go through several different channels to find the support they needed. Some parents said that if they had received support earlier, more acute problems could have been prevented. Opportunities to include fathers, both as a resource and in terms of their own unmet needs, were sometimes missed.

The best practice in Oxfordshire was experienced as excellent, both in terms of support and of joined up work. Breastfeeding support for example is an area where experiences varied widely, some reporting it as excellent while for others it was very hard to find or to access. The skills of staff in listening, understanding, assessing and identifying further need also seem to vary widely. The importance of warm and trusting relationships was emphasised again and again throughout the interviews and responses.

We hope that the voices captured here will influence managers and joint commissioners of services whenever there are opportunities to build on and to disseminate best practice, as well as when considering training and staff development needs.

The recommendations are:

1. In the light of current cuts to children's centres, everything possible should be done to ensure clear pathways of support for families and the continuation of open access support. The responses we gathered demonstrated overwhelmingly the importance of these local children's centres, the open access, universal services they offer and the role they play in enabling joined up provision and support.
2. There should be a cross agency system to enable earlier identification of parents who are in need of emotional and mental health support, particularly those who are reticent or find it difficult to ask for help. Better linkages and communication need to be made between different services to ensure all professionals can access basic information about people to avoid constant repetition. A key worker could then be a named point of contact/information and joined up support. This happens in a few cases with the Team Around the unborn Child (TAC), but a lighter touch version with wider application is needed.
3. Consistency of care needs to be improved. If all health visitors and midwives offered the standards of care that the best offer, then the support in Oxfordshire would be superb. Examples of best practice which can be more widely adopted, could be identified and highlighted. Parents are happy to assist with this. Respondents were all too aware of the pressures on staff, particularly midwives, but there was a feeling in several cases that the midwives' checklist was a tick box exercise rather than a flexible and living tool to enable the identification of further support needs. Midwives should be offered more training/ professional development about the most effective use of this tool.
4. Training needs emerge in two areas, where the gap between the best practice experienced by some and the absence or paucity of support experienced by others is greatest. These are:
 - Support that is available for people who are struggling emotionally needs to be more widely and consistently available, with health professionals across agencies trained to be able to identify those in need earlier in the process.
 - Awareness raising and training for health professionals is needed to ensure that fathers are fully included wherever possible and that their emotional needs are also part of the picture.
5. Breastfeeding should be encouraged and support provided to help people who want to feed. This support needs to be universally understood and not the preserve of a few specialists.

Who We Are

1001 Critical Days¹ is a national campaign that aims to raise awareness of the importance of the period from conception to around the child's second birthday. It is a crucial time in the life of the infant/child and of the family. It's the most significant period in terms not only of physical development of the child, but in the forming of attachments and the development of the brain, when there is great potential to influence long-term health and social outcomes for the baby. The mother's mental health is an important component of the baby's experience. The national 1001 Critical Days Campaign has at its centre an all party parliamentary group with signatures of support from eight political parties.

Drawing on the success of the national campaign, a local group was set up which aimed to increase awareness of the significance of the first 1001 critical days of a child's life in Oxfordshire. An initial meeting was held in March 2015, attended by 20 people from health, social care, research and the voluntary sector. The clear priority arising from that meeting was to increase the prominence of the parent's voice in Oxfordshire, giving the opportunity to as wide a range of parents as possible to articulate what is important to them during that crucial period and to identify what had been helpful and what they believed could have been different. The local coalition then applied to Healthwatch Oxfordshire for funding to support the project. The following organisations are represented in the coalition:

- OXPIP: Oxford Parent Infant Project (the host body for the funding)
- Family Links
- PEEPLE
- Oxford Health NHS Foundation Trust
- NHS England, Children and Maternity Strategic Clinical Network
- Oxford University Hospitals NHS Foundation Trust
- Royal College of GPs
- The Blackbird Academy Trust
- The Mulberry Bush School
- Oxfordshire County Council
- Donnington Doorstep Family Centre

Funding from Healthwatch Oxfordshire was agreed to pay for i) a survey of parents with recent experience of the perinatal period (i.e. the time leading up to the birth, birth itself and the post-natal period) and ii) an event to allow for a more nuanced discussion of the issues.

What We Did

An online survey was set up through Critical Research². This was publicised through the following:

- A featured television interview on BBC South Today in December 2015
- Radio interviews with coalition members on BBC Oxford in December 2015
- Flyers and posters which were distributed to:

¹ <http://www.1001criticaldays.co.uk/>

² https://www.criticalsurveys.co.uk/scripts/dkwebserve_adv.cgi?survey=7112

- a number of children's centres across Oxfordshire
- Health Visitor clinics
- The maternity unit at the John Radcliffe Hospital where they were put into all birth packs
- Emails to numerous distribution lists as well as via local websites such as OXPIP's and Healthwatch Oxfordshire's
- Facebook postings
- Other websites, e.g. Oxfordshire page of NetMums

Surveys were completed online (a postal return was offered but not used). The initial response rate of completed questionnaires was not very high. Consequently, a second wave of advertising the questionnaire through the same channels was undertaken in March 2016. In total thirty six questionnaires were completed and the qualitative responses were analysed by a researcher from Oxford University. The survey findings from the questionnaires are summarised below.

As part of the survey people were asked if they were interested in attending an event. Invitations were then sent to those who expressed an interest as well as through other channels. The event was held in April 2016 and three people attended. As a result, we decided to do more in depth interviews with those people plus one other who came forward but couldn't make the event.

When we planned the project, back in the spring of 2015, we were not aware of the threat to children's centres that surfaced in June 2015. This happened a few months after the project was planned but before we eventually went live with the survey. The campaign to save the children's centres has been highly effective at getting the parents' voice at the heart of the debate about the proposed changes to children's services in Oxfordshire. One of the unofficial aims we had at the outset was to "make some noise", to support parents to express their opinions loudly and clearly to policy makers. This has clearly happened powerfully with the children's centres campaigning but has, almost certainly, left us in the shade as a means of engagement for this project. The overwhelming focal point for parents and others with an interest in the early years was the campaign to keep the Children's Centres open.

The potential impact of the cuts was also unsettling for the organisations involved in the project, reducing the time available for the project. In addition, the project lead left OXPIP part way through the project, which resulted in some loss of momentum and capacity for the work. Nevertheless, strong messages emerge from the particular focus of our research, many of which relate to the strong sense of connectedness, relationship and interagency cooperation which parents experience in the Children's centres and which they consider vital to the efficacy of future services.

What We Found - the online survey

After much discussion about the survey format most likely to encourage a high response rate from a wide range of participants, it was decided to keep it as simple as possible, asking two open questions and inviting a free text response.

Participants were asked:

Thinking about your family's social and emotional wellbeing during the period when you (or your partner) was last pregnant up to your child's second birthday:

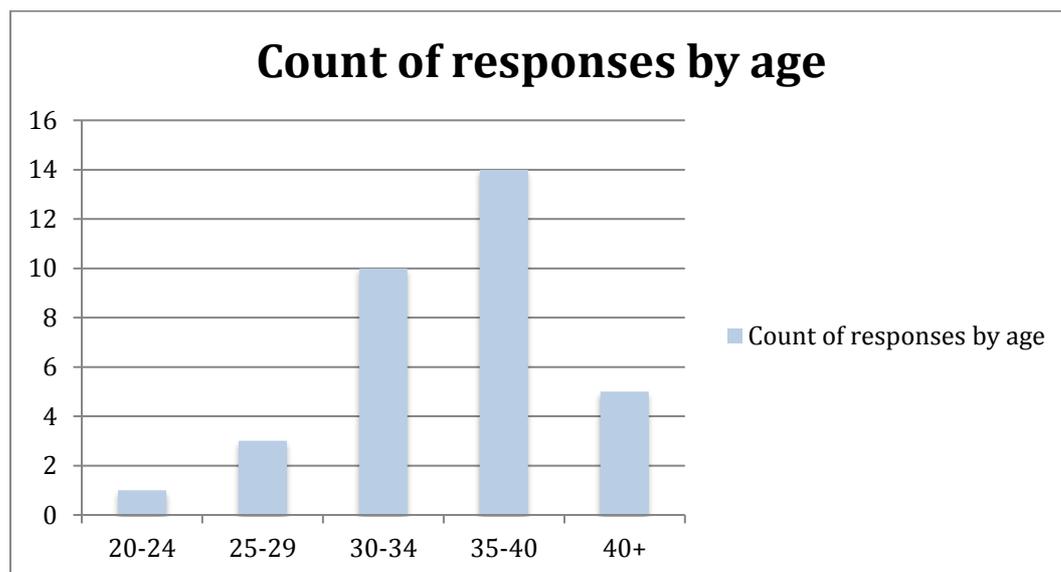
Q1. The service or support that helped most during that period was...

Q2. The service or support that would have been good to have was...

We had 36 responses from 14 different postcode areas covering the city as well as Banbury, Bicester, Abingdon, Wallingford, Thame and a number of rural areas.

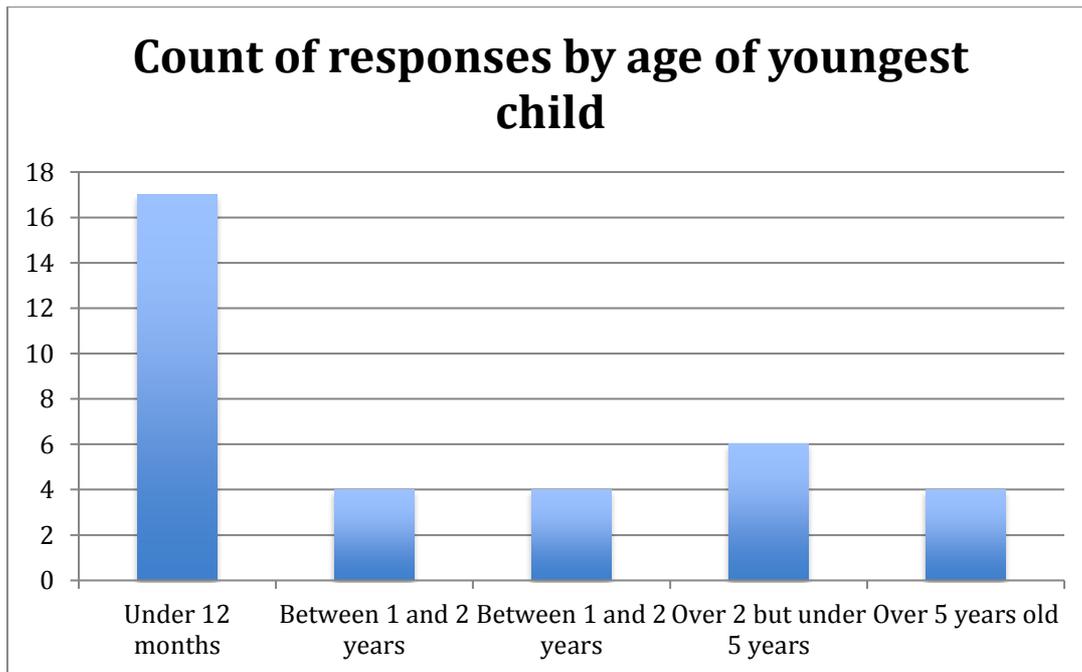
The majority of respondents were White British but there were also responses from White - other, Asian/Asian British - other and Black /African/Caribbean groups.

The graph below shows the number of people who responded broken down by their age. It seems clear from the responses that while the survey reached a wide geographical array of parents, it drew most heavily from those who are older than average, more likely to be white and more likely to be married. The interviews similarly focused more on people living in the city (due to them taking place in the city).



All but one of the respondents were female. Of those who declared their marital status 76% were married, with the rest split equally between cohabiting and single.

The graph below shows the breakdown of the number of people by the age of their youngest child.



Please see Appendix A for eloquent and detailed responses to the survey questions

The service or support that helped most

The most popular themes to emerge in response to this question were:

- Children's centres (support from staff, groups) (16) Many individual centres were mentioned as well as health visitor and Baby Cafe support available in children's centres, stay and play sessions and other groups
- Support from midwives (10) Particular community midwife teams were mentioned as well as pre-birth check ups(when there was sufficient time given) and post birth visits
- Health visitors (7) Support was valued both at drop ins and individual visits
- Additional support organisations (NCT, La Leche League, Baby Cafe, Perinatal Service) (11)
"The service I have been provided by IPPS [Infant-Parent Perinatal Service] has literally been a lifeline. It is a privilege to be offered such care and I cannot praise it more"
- Support from medical staff (GP, hospital consultants, SCBU) (5)

The service or support that would have been good to have

The most popular themes to emerge in response to this question were:

- Additional health visitor (HV) support (more time with HV at each appointment, more appointments) (8)
“Health visitors with more time available and who listened!”
“The removal of private one to one appointments with health visitor means that I speak to the doctor a lot more, wasting their time with what I think are basic health visitor queries.”
- More support in the following areas:
 - a. Support with breastfeeding (in early days, at home) (4)
“Greater support and information about breastfeeding while in hospital”
 - b. Emotional support not just physical care (7)
“More support for the emotional aspects of pregnancy and early parenthood and not just the physical side of things”
 - c. Better support for mental health issues
“Quicker faster treatment for post natal depression”
“Support group for new mums who were also struggling with mental health problems”
 - d. Availability of more support groups (8)
 - e. Opportunities to meet other mums (6)
- Consistency of care (same midwives for antenatal care, transfer of information between healthcare professionals) (5)
“Much better health support for me (the mother) in the early days. I had problems with stitches and got lost in the gaps between the midwives, health visitors, GP and hospital.”
“It would be good to have more link up between the services”
- Greater information available (how to contact midwife in early days, where to find resources) (7)
“More frequent / closer support from health visitor or similar - perhaps in an online format / forum where questions could be posed if not possible to attend drop in sessions e.g. once back to work.”

What we found - in depth interviews

Four interviews were conducted with mums using a semi-structured approach. (See Appendix B for the questions which formed the basis for the semi structured discussions) Working with a checklist of key services and events, each person talked through their experiences from conception through to the current day. Following this timeline enabled us to get a rich picture of each person's experience of becoming pregnant and then becoming a mother. The mothers we spoke to had very different backgrounds and experiences but highlighted many of the same issues.

Overall it is worth saying that all the mothers felt that they had had many positive experiences of services and support. There was a clear understanding that there is a lot of support out there "if you go out and look". There was also recognition that many services are struggling with high caseloads alongside changes and cuts to the wider services they form part of.

The main areas that these interviews highlighted are set out below along with a commentary and quotes from the mothers.

Vital role of children's centres

The transition into a children's centre (CC) can be a challenging one, and the mothers spoke positively of support they had received in accessing their local children's centre. One had been supported by a health visitor who helped greatly both through accompanying her on her first visit and through running a group in the centre that was the mum's first service at the centre.

Smaller, invitation only groups, were critical for one mum to build her confidence and enable her to access mainstream stay and play services. When she first tried to attend the stay and play it was too much and she felt excluded and overwhelmed. By starting in a smaller group she was able to build her confidence and then move onto the stay and play.

Children's centres were felt by all to be the place where different services got connected, where the "dots got joined up" and there was an "understanding of what was available". A mixture of information from professionals, peer advice and support and just the very basic opportunity to get out somewhere you are confident you will be welcomed made CCs critical for many people in ensuring they didn't need to access more costly services.

"Children's centres are somewhere you can go that you know you'll get some help"

Inadequate support for emotional and mental health needs

Experiences of the quality of support from health visitors (HV) were very mixed, and there was clearly a feeling that it was luck of the draw who you got. One mum commented that her HV talked about herself more than asking how the mother was.

Another said that she spent an hour talking to one HV about her professional work and that this felt very validating and positive. Towards the end of the conversation she

said she was struggling a little to which the HV said “you’re eloquent and confident I’m sure you’ll ask for help if you need it.” Her response (internally) was that she just had asked, but it had been missed. The opportunity to identify someone who needs emotional help is often fleeting and needs to be handled with sensitivity.

There is a stigma to admitting you aren’t coping, making it hard for people to speak out when they do need support. When questions were asked they felt like checklists. There was often a sense that you couldn’t say you needed help because the person speaking to you didn’t have the time to be able to offer any support. This created the sense that it was a silent problem, the quote that has given the title to this report.

Fathers present at the start of two of the interviews said that they would like to have been asked about how they were feeling and the emotional impact of such a momentous event on their lives.

While some services are available to help meet people’s emotional needs, they are often patchy and over-subscribed. Talking Space, IPPS (the Infant Parent Perinatal Service), Family Links, HomeStart and OXPIP (Oxford Parent Infant Project) were all mentioned as services that could offer fantastic support to mums but were either restricted or limited by their capacity and funding.

“OXPIP would have been fantastic”

Lack of joined up services/ consistency of care

One mother was on medication for depression when she became pregnant and found the lack of join up between her GP, Community Mental Health Services, the psychiatrist and her midwife frustrating. This was a consistent theme across all the mothers we spoke to with primary, secondary and other community care services not linking up and sharing information effectively.

Changeovers between different staff in the same service and the lack of continuity of care could be problematic, with the age-old problem of people having to repeat information to numerous professionals.

Mothers’ experiences of the Community Midwife Team (CMT) varied from never having heard of them (they offer a 24hr support line) to finding their support invaluable, including over the phone in the middle of the night.

A clear wish for allocated key workers was expressed, both for the midwife and health visiting services. While acknowledging there are staff changeovers and people cannot work all the time, having a named individual to come back to was very helpful. One woman found her support from the CMT very useful and valued highly being able to ask for someone who knew her history and didn’t have to have everything repeated.

More consistent support for breastfeeding

Breastfeeding was felt by several of the mums to be central to their early experiences of motherhood.

“It takes over everything”

“It goes to the core of how you feel as a mother”

More support was wanted both in hospital and at home. There was a sense that while there is some support for mums trying to breastfeed there was an assumption on the part of many that bottle-feeding was better and that turning to the bottle and formula milk was a solution to difficulties experienced in the early stages of breastfeeding.

Breastfeeding was also recognised as a central activity to bonding with the baby.

“I felt so connected to him when I was breastfeeding him”

And while it was clear that bottle-feeding could offer the same closeness between mother and infant, there was a sense both of loss and of guilt on the part of mothers who wanted to breast-feed but were not given sufficient support to persist when difficulties arose.

Again there was very mixed experience of HVs ability to provide support for breastfeeding, with one mum feeling that she knew considerably more about lactation and breastfeeding than her HV. There also seems to be patchy knowledge about medication and breastfeeding with one mum getting different guidance from different health professionals as to what she could and could not take. Another mother had been given breast-feeding advice by as many as 10 different professionals/ supporters and, while she acknowledged that it was great that support was there, some of the advice had been conflicting and therefore confusing

Experience at the John Radcliffe hospital was that there was limited breastfeeding support, with the staff that there were not having sufficient capacity and also not working at weekends.

Conclusions

A great deal of good work is being done in Oxfordshire and there was considerable praise for individuals and services across a range of organisations and sectors. There was also recognition that the county council is in very difficult situation with the level of cuts it is facing and that many people are being asked to dismantle services that they believe in and helped to create. It is in the knowledge of this good work and the challenges that are being faced that the recommendations below are made.

A number of recommendations for local commissioners and providers clearly arise from the work:

The recommendations are:

1. In the light of current cuts to children’s centres, everything possible should be done to ensure clear pathways of support for families and the continuation of open access support. The responses we gathered demonstrated overwhelmingly the importance of these local children’s centres, the open access, universal services they offer and the role they play in enabling joined up provision and support.

2. There should be a cross agency system to enable earlier identification of parents who are in need of emotional and mental health support, particularly those who are reticent or find it difficult to ask for help. Better linkages and communication need to be made between different services to ensure all professionals can access basic information about people to avoid constant repetition. A key worker could then be a named point of contact/information and joined up support. This happens in a few cases with the Team Around the unborn Child (TAC), but a lighter touch version with wider application is needed.
3. Consistency of care needs to be improved. If all health visitors and midwives offered the standards of care that the best offer, then the support in Oxfordshire would be superb. Examples of best practice which can be more widely adopted, could be identified and highlighted. Parents are happy to assist with this. Respondents were all too aware of the pressures on staff, particularly midwives, but there was a feeling in several cases that the midwives' checklist was a tick box exercise rather than a flexible and living tool to enable the identification of further support needs. Midwives should be offered more training/ professional development about the most effective use of this tool.
4. Training needs emerge in two areas, where the gap between the best practice experienced by some and the absence or paucity of support experienced by others is greatest. These are:
 - Support that is available for people who are struggling emotionally needs to be more widely and consistently available, with health professionals across agencies trained to be able to identify those in need earlier in the process.
 - Awareness raising and training for health professionals is needed to ensure that fathers are fully included wherever possible and that their emotional needs are also part of the picture.
5. Breastfeeding should be encouraged and support provided to help people who want to feed. This support needs to be universally understood and not the preserve of a few specialists.

Appendix A: 1001 Critical Days Questionnaire summary

Questionnaire items

Thinking about your family's social and emotional wellbeing during the period when you (or your partner) was last pregnant up to your child's second birthday:

Q1. The service or support that helped most during that period was...

Q2. The service or support that would have been good to have was...

36 people completed the questionnaire

Verbatim responses

Q1A: The service or support that helped most during that period was:	Q1B: The service or support that would have been good to have was:
Midwife just before birth but otherwise very little help. The lovely team of community midwives.	Health visitor support, breastfeeding support, intros to other mums.
Childrens centre	Support group for new mums who were also struggling with mental health problems
Children's centre staff from Heyford Silver Star Unit JR Oxford	Quicker faster treatment for post-natal depression Faster access to paediatric allergy services faster access to paediatric psychology
Community midwives in Wantage	Counselling after difficult labour, someone who could help me cope emotionally in the first few days when I was finding it difficult to look after my baby due to medical complications.
Babycafe	Health visitors with more time available and who listened!
Elm's Road childrens centre, Botley	More support after I went back to work- it was a really difficult time and although there were groups and things, they were all during the day and I couldn't get to any! Evening/weekend groups would have been really helpful.
La Leche league	

Q1A: The service or support that helped most during that period was:	Q1B: The service or support that would have been good to have was:
NCT antenatal course Baby Cafe	More support for the emotional aspects of pregnancy and early parenthood and not just the physical side of things
Nurses in scbu. GP. Family. Children's centre church community.	More health visitor visits
Children's centre	More widely advertised and accessible services for birth preparation, like yoga for pregnant women , and NCT birth preparation classes
Midwife Baby groups at children's centre Private one to one appointments (inc drop ins) with health visitor - since removed	The removal of private one to one appointments with health visitor means that I speak to the doctor a lot more wasting their time with what I think are basic health visitor queries. My previous health visitor was also able to prescribe mess for baby's eczema which I also have to see the doctor for now. This feels like a step backwards and places more pressure on doctors. Also children's centres offer amazing support but there are no groups for toddlers and babies together that I can find which has been a bit isolating.
La Leche League	Baby Cafe (didn't exist in my area at that time)
Access to breastfeeding support and advice and midwives at Baby cafes	Greater support and information about breastfeeding while in hospital
Babycafe Oxford. Florence Park, East Oxford and Rose Hill locations	More frequent / closer support from Health visitor or similar - perhaps in an online format / forum where questions could be posed if not possible to attend drop in sessions e.g. once back to work. Also 6 monthly follow up call / visit just to check in and see if any issues / support required
Children's centres	

Q1A: The service or support that helped most during that period was:	Q1B: The service or support that would have been good to have was:
Children's centres, and NHS	affordable high quality childcare after maternity leave ended
Baby Cafe	Afternoon stay and play sessions
Children's centre, including baby cafe and play sessions	Much better health support for me (the mother) in the early days. I had problems with stitches and got lost in the gaps between the midwives, health visitors, GP and hospital.
Children's centres	If I had been more aware of what exactly was on offer at the Children's centre i.e Peep
Children's centre stay and plays	Parenting classes e.g. Discipline, managing parents anger, sibling rivalry
My health visitor and Oxpip	I was fortunate enough to have that right team of people to support me in my time of need.
Infant Parent Perinatal Service (IPPS)	Better midwife support both during pregnancy and post-nataly.
The midwife at the GP and the Day Assessment Unit.	I can't think of a service. It would be good to have more link up between the services.
I have received no support whatsoever	Psychological pre- and postnatal counselling would be great
Midwife check ups Health Visitor advice after birth Midwife visits in first ten days after birth	Earlier opportunity to ask questions, pre 12 weeks pregnancy from midwife. Didn't know about MLU facility until appointment booked for 12 weeks
Health Visitors	More contact with professionals after 6 weeks via arranged meetings as I am reluctant to contact them in case I was perceived as asking silly questions or wasting time

Q1A: The service or support that helped most during that period was:	Q1B: The service or support that would have been good to have was:
Donnington Doorstep. Talking Space.	Access to parent infant therapy. Support at home. Peer support
Health worker visits Local Baby Centre	Maybe to have been given more knowledge about NCT classes after and before birth. I had heard of them but no one gave me any information about this and I might have found this support useful. Apart from that i found i got great support from the Health visitor and my local children's centre
Stay and play sessions at the children's centre	Breastfeeding support who comes to the house. I was not organised to go to a baby cafe in that first 10 days when I needed help
Health visitor drop-in at Botley Children's Centre	A consistent health visitor that I could call when necessary
Having a good friendship group to turn to.	A slightly less judgemental health visitor and medical system
The Midwives in Chipping Norton	The same midwives for birth as for antenatal.
My health visitor.	Someone to fight our corner when we received a revenge eviction notice just before the birth, and someone to help me with domestic relationship pressure and help him with anger etc.
<p>Infant-Parent Perinatal Service</p> <p>The service I have been provided by IPPS has literally been a lifeline. It is a privilege to be offered such care and I cannot praise it more, particularly Della.</p>	<p>N/A</p> <p>I feel that I have been provided care from every service I required, i.e. health visitor, GP, midwives (particularly at the Spires where I gave birth).</p>
Community midwives	More consistent level of care provision in hospital I.e. The midwives and medical assistants varied massively in care quality which really impacted our care.

Appendix B

Perinatal experiences - semi structured interviews

Thinking back to the various stages of getting pregnant through to where you are today, can you tell me about how each stage was for you, whether there were any particular problems, if there was any help that was particularly useful and if there was anything that would have helped that you didn't get?

Stages:

Getting pregnant

Medical confirmation of pregnancy

GP - how were they?

Midwife - getting referred, meeting, support

Being pregnant

Birth planning/ pre-birth support

Birth

Health Visitor

Support in the first few days- e.g. breastfeeding, anything else?

After the first couple of weeks - accessing other services and support (friends, family, children's centres, HV clinics etc.)

Other support - e.g. groups, baby cafes, counselling, therapy

As your baby grew - community centres and activities, wider society

Where you are now

Any other comments or reflections?