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Early care and education for young children born prematurely:

Parents' experiences

Background and context

Each year in England, around 10,000 children are born very preterm (at less than 32 weeks gestation) and a further 60,000 are born moderately preterm (at 32-36 weeks gestation). The number of preterm births has increased in the last two decades, and more preterm children are surviving due to improved neonatal care (National Neonatal Audit Programmed, 2015).

However, the prevalence of cognitive, behavioural and emotional problems in preterm populations has not changed. In particular, children born preterm have been found to experience specific learning problems including difficulties with mathematics, visual-spatial skills, memory and attention.

There is still much we do not know about the nature and spectrum of these learning difficulties, their long term consequences, and how to deal with them. In particular, there is controversy about whether moderately preterm children experience similar but milder learning problems than children born very preterm. Teachers and educational psychologists receive little formal training about preterm birth and are often not aware of appropriate strategies to support preterm children in the classroom. Informing teachers about the special constellation of problems following preterm birth is crucial in preparing them to support the growing number of preterms entering schools in the coming years (Campbell, 2015; Carpenter et al., 2015).

Studies have explored parents' experiences of having a child born prematurely. However, these studies have generally focused on the months immediately following the birth and have taken a health and social care perspective (Harvey et al, 2013; Garfield et al, 2014; Gray et al, 2013). Quantitative studies have also examined the development of children who were born prematurely and have identified the learning difficulties that they face during early childhood (Marlow, 2004; Johnson et al, 2010; Costeloe 2012). Parents' experience of early years education is an under-researched area.

The benefits of early care and education early intervention (EI) have been well documented in policy and research in terms of improving outcomes for children at risk of or identified with SEN. Whilst not all children born prematurely will be identified with Special

Educational Needs, ongoing monitoring of their learning and development has the potential to ameliorate any future delays or difficulties.

Aim of research

This study aimed to explore the early care and education experiences of children born prematurely through reports from parents. Research questions include:

1. What are the early social experiences of young children born prematurely (as reported by parents)?
2. What are parents' memories of their children's developmental milestones?
3. Where children are attending early years settings, what are parents experiences of this, were there any difficulties/problems in finding suitable childcare provision?
4. What advice/support do early years workers need to support children born prematurely and their families?

Methods

An online survey was promoted widely via social media and existing contacts. The survey was also promoted by BLISS charity for babies born premature or sick. A total of 209 parents responded to this. Parents were invited to leave their contact details if they wished to participate in an interview. A sample of thirteen parents were invited and consented to participate in an interview. The sample was selected to provide a maximal variation sample of ages and other social demographics. Twelve mothers and one father were included in the sample. Interviews took place by telephone at a time and date convenient to the parents. A structured interview schedule guided the discussion. Topics for questions included experiences in hospital, information provided in hospital and on discharge, early help and support from professionals and families, experiences of parent and toddler groups, pre-school education and transition to school, primary school entry. The purpose of the interviews was to provide more in-depth answers to some of the themes arising from the survey in relation to hospital experiences, early help and support from professionals and pre-school, primary school education.

Results

Part 1: Survey findings

1.1: Parents experiences in hospital

Parents were asked about how much information they were given about their baby during their stay in hospital and who provided the information.

As can be seen from Figure 1, the majority of parents (over 120) were given lots of information about practical aspects such as 'feeding' and their role in their baby's care. Over half were given some information on prematurity. Nearly 100 were given little or no information, nearly 80 were given some information and only 38 were given lots of information on long term outcomes for their baby.

How much information parents were provided

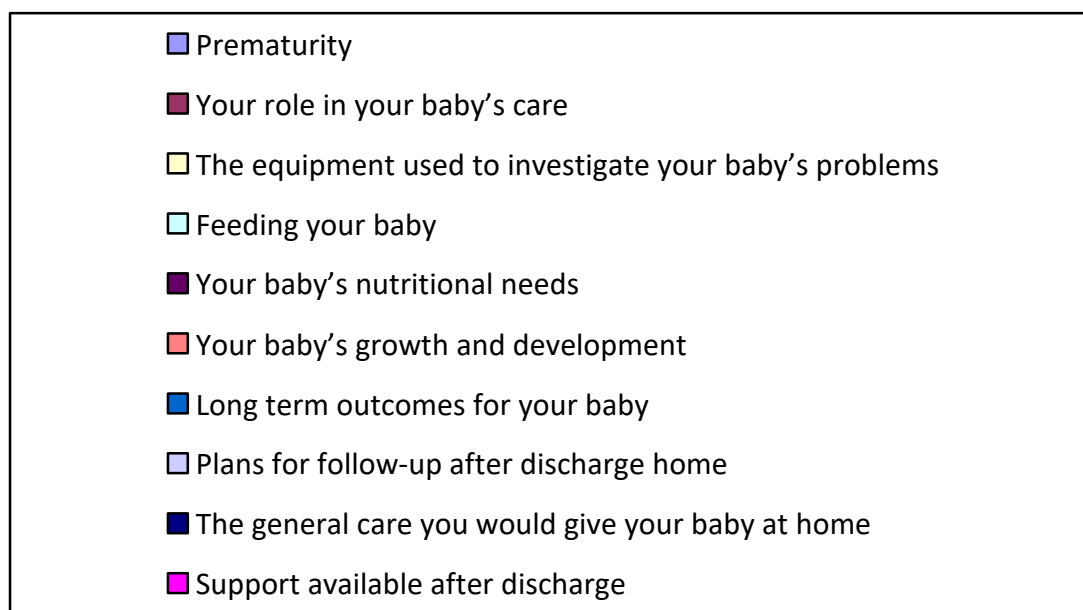
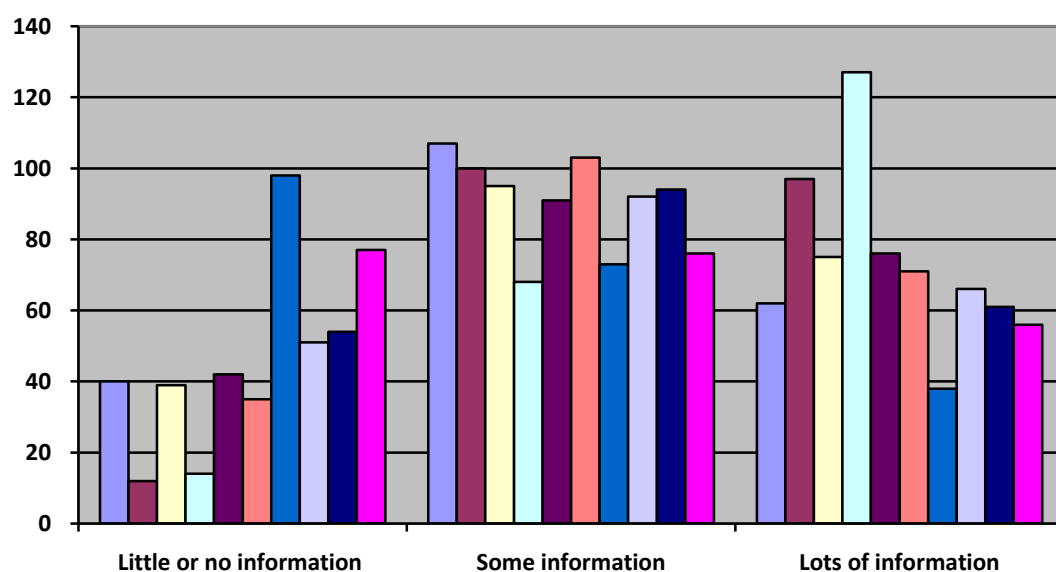


Figure 1: Information provided to parents in hospital

Some parents said that hospital staff had focused on practical and immediate aspects of neonatal care:

I was very concerned about the impact it would have on his development, but the focus in the hospital seemed to be just about immediate survival and getting him well enough to go home.

The likely outcomes [for my baby]. Day by day we didn't really know what the ultimate outcome would be. [I] understand that's no-one would really know this but felt there was no confidence given. In hindsight I know that we had

relatively straightforward cases. Had we known this at the time we would have been more relaxed.

Other parents reported that they were not provided with information on even basic aspects of how they could provide care for their baby and this impacted upon their confidence as a parent:

I would like to have known more about how I as a mother could help my baby. Kangaroo care for example was mentioned, but I wasn't given much information on when I could hold my baby, how long to hold him for, how to hold him. All of these things meant I didn't like to do it too much because I was scared it would be detrimental to his well-being.

There also seems to be a paucity of information provided for parents about support for themselves and / or their baby after discharge. Nearly 80 parents reported little or no information; the same number reported some information and only 58 reported receiving lots of information on this aspect.

Fifty nine parents had residual questions on leaving the neonatal unit, as demonstrated in Table 1 below. Most parents wanted to know more about their baby's long term developmental outcomes, but a number also wanted to know about basic aspects such as feeding, basic care and whether their baby would survive:

I didn't actually know if my baby was likely to live, I was scared to ask. We went about a week thinking she could die from the infection ... had until I finally asked a doctor who told me she would definitely fight it.

What were their likely outcomes? What might life hold for my son who was disabled? What help would be available to our family?

Discharge plan was non-existent and felt rushed; I didn't understand what follow-up we should expect or how to get help with issues. We live rurally and were out of reach of the post-discharge outreach team so only had our HV to rely on - who was good but not specialist in prem issues.

Table 1: Information not provided to parents that they would have liked to have known

Baby's health/well-being	
Future long term prospects/outcomes for baby	30
Information about breastfeeding a premature baby	5
Feeding and care at home/Kangaroo care	4
Whether the baby would survive	3
Information about the baby's cardiac problem	2
Haemorrhage occurrence	2

More information generally	2
Baby's day to day well-being	1
Reasons for fits	1
Reasons for cranial ultrasound	1
Information about bottle feeding a premature baby	1
Implications of blood condition	1
Impact of birth trauma on baby	1
Vaccinations prior to due date	1
Maternal health/well-being	
Implications on maternal mental health of premature birth	2
Professionals	
Lack of knowledge amongst HVs/nurses about premature birth	4
Conflicting advice between professionals	1
Information about identity of baby's consultant	1
Practical/financial information	
Long-term stays/financial information	3

1.2: First experiences in contact with their child

As can be seen from Figure 2 below, the majority of parents did not touch or hold their baby in the first hours or the first day following birth. For many this happened in the first week, for 35% of parents, holding their baby only happened after a week had passed.

First experiences between parent and child

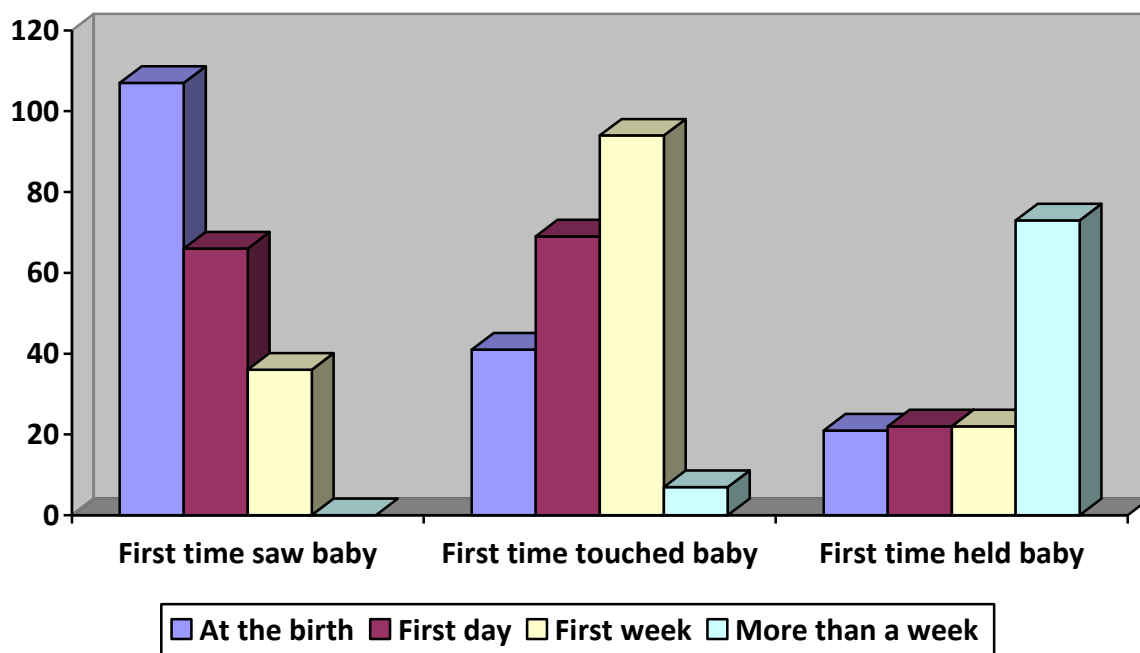


Figure 2: First experiences for parent and child in bonding

Number of weeks gestation	See baby				Total
	At birth	First day	First week	More than a week	
23	4	3	1	0	8
24	5	2	1	0	8
25	7	3	2	0	12
26	9	8	3	0	20
27	6	3	1	0	10
28	7	15	2	0	24
29	8	7	10	0	25
30	8	6	8	0	22

31	9	6	2	0	17
32	9	3	4	0	16
33	14	7	0	0	21
34	10	1	1	0	12
35	7	2	1	0	10
36	4	0	0	0	4
Total	107	66	36	0	209

Number of weeks gestation	Touch				
	At birth	First day	First week	More than a week	Total
23	1	4	1	2	8
24	1	2	5	0	8
25	1	5	5	1	12
26	0	8	11	1	20
27	2	3	5	0	10
28	2	8	13	1	24
29	2	4	19	0	25
30	3	3	14	2	22
31	2	9	6	0	17
32	4	4	8	0	16
33	8	10	3	0	21
34	7	4	1	0	12
35	4	5	1	0	10
36	4	0	0	0	4
Total	41	69	92	7	209

	Hold				
Number of weeks gestation	At birth	First day	First week	More than a week	Total
23	0	0	1	7	8
24	0	0	0	8	8
25	0	0	1	11	12
26	0	0	6	14	20
27	1	1	4	4	10
28	0	1	11	12	24
29	0	1	15	9	25
30	2	1	16	3	22
31	1	2	12	2	17
32	0	3	12	1	16
33	8	4	8	1	21
34	4	5	3	0	12
35	3	4	2	1	10
36	3	0	1	0	4
Total	22	22	92	73	209

Some parents commented that delay in seeing, touching or holding their baby had a detrimental effect on their long term relationship with their child.

Not being able to stay with the baby was terrible. It was over-crowded. The nurses were very helpful and kind on the NNU. But on the maternity ward it was terrible. I wasn't allowed to see my baby until late the next day after having him. Just shown a picture. The mental scars will be there forever. It took a long time to bond with my baby and even today this bond is very different to my other son.

Most of the time I felt like I was visiting someone else's baby. I had to ask permission to feed, change or get my baby out for a cuddle. I know this was for safety of baby as she was fragile but it just made me think I wasn't capable of being a mother.

It was traumatic but the NICU staff were amazing. The most unbearable part was being sent home and having to leave my baby behind. Still trying to get over that trauma.

1.3: How parents received information about their baby during their neonatal stay

A wide variety of professionals talked to parents about their baby during their neonatal stay. However, the most often reported professionals were nurses and doctors with 203 (nurses) and 183 (doctors) parents reporting having received information these professionals. In addition, 65 parents searched online for information.

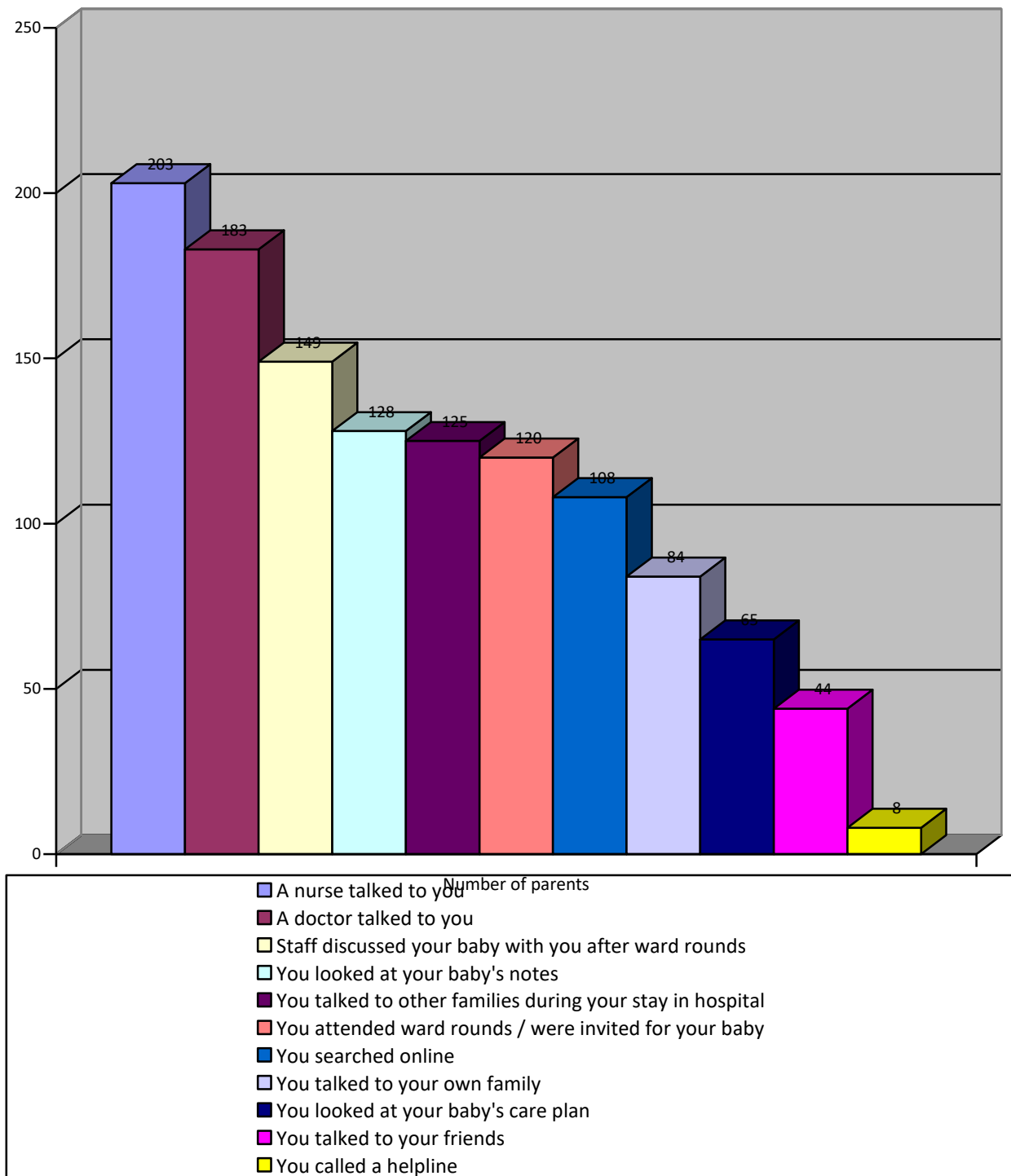


Figure 3: Which professionals talked to parents about their baby

1.4 Parents feelings about their hospital experience (180 responses)

Many (70) parents said that they felt supported by staff and that their hospital stay had been a positive experience:

It was very hard emotionally but all of the nurses were lovely and gave my husband and me lots of advice in the early days of how to look after our baby. Being able to stay in the hospital for the first few days was so important as I could go and see her at any time of day/night.

The NICU staff were amazing, but emotionally, the whole experience has led to me (mum) suffering PTSD and depression.

However, a similar number of parents described the experience in negative terms as emphasised in the comments below:

It was incredibly stressful and the most traumatic experience I have ever had. I have been diagnosed with PTSD.

Some parents acknowledged that although it was a stressful time, support from staff reduced stress and anxiety and increased positive aspects of care:

At the time it was scary and emotionally it was a roller coaster, but looking back there were benefits to the supportive community within the hospital, as I learnt a great deal about prematurity, newborn care and even about myself.

For some parents there was a different experience between being on the neonatal ward and the maternity ward in terms of their experience. For some parents, the lack of support from staff had a detrimental effect on parent / child bonding and maternal well-being:

I will be forever grateful to the hospitals that cared for my son and helped him live and thrive; I could not fault his care. However, as a mother, I felt completely let down in many ways (although not diagnosed, I feel in hindsight that I probably suffered mild depression and some form of stress/trauma during the whole experience, which has left me fearful of having more children).

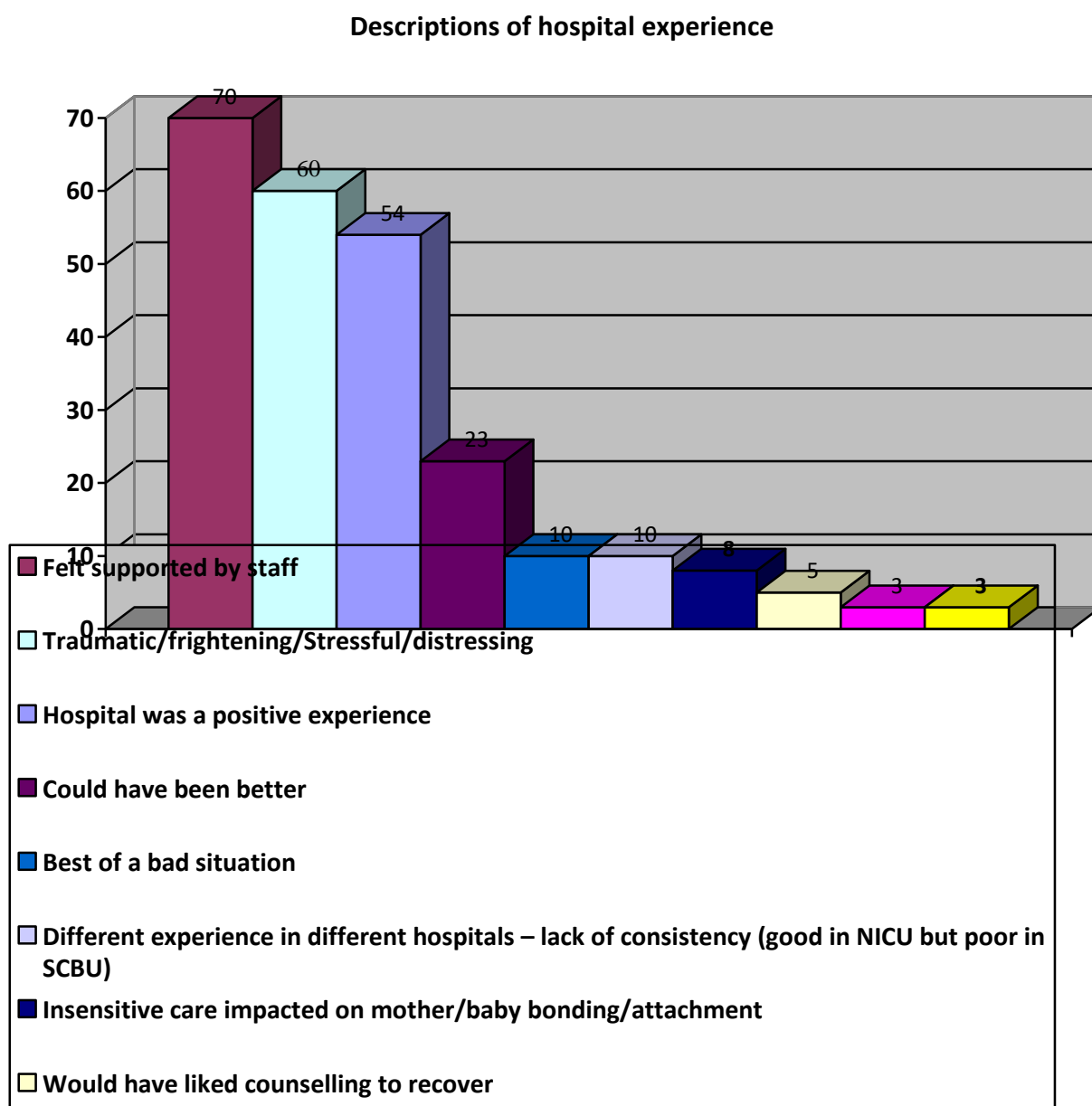


Figure 4: Parents’ descriptions of their hospital experience

1.5: Support after hospital

After leaving hospital, parents had a wide range of support networks available to them. The majority of participants (60.3) said that their partner had been extremely helpful and a further 33% said that their parents had been extremely helpful. Nearly 40% (38.8%) said that their GP was only sometimes helpful.

Table: 2 Support networks

How helpful were these people	Not available	Not helpful at all	Sometimes helpful	Generally helpful	Very helpful	Extremely helpful	Not applicable
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My parents	13.9%	4.8%	15.3%	14.4%	16.7%	33%	1.9%
My partner's parents	16.3%	23.4%	21.5%	15.8%	9.1%	12%	1.9%
My relatives	18.7%	15.8%	23.4%	20.6%	11%	8.6%	1.9%
My partner's relatives	19.7%	30.8%	19.7%	14.4%	6.7%	4.3%	4.3%
My partner	2.4%	2.4%	7.2%	9.6%	16.7%	60.3%	1.4%
My friends	6.3%	14.5%	23.2%	25.1%	20.8%	8.2%	1.9%
My partner's friends	20.3%	27.5%	21.7%	11.6%	9.2%	3.9%	5.8%
My own children	19.4%	3.9%	3.4%	3.9%	5.8%	5.8%	57.8%
Other parents	17.8%	7.4%	21.8%	12.4%	10.9%	7.9%	21.8%
Colleagues at work	19.9%	26.7%	17%	8.3%	8.7%	2.9%	16.5%
Parent and toddler group	15.5%	23.2%	23.7%	10.6%	3.4%	2.4%	21.3%
Social groups/clubs	23.4%	20.5%	12.7%	11.7%	1.5%	1.5%	28.8%
Places of worship/religious organisation	26.7%	7.3%	4.9%	3.9%	3.9%	4.9%	48.5%
My family or child's GP	3.4%	18.9%	38.8%	16.5%	10.2%	5.8%	6.3%
Pre-school/nursery workers	14.8%	4.4%	16.3%	9.9%	11.3%	4.4%	38.9%
Professional helpers	5.8%	17.3%	26.4%	19.7%	13.9%	11.1%	5.8%
School staff	17.8%	7.9%	10.9%	5%	6.4%	1.5%	50.0%
Early intervention programmes	22.8%	9.4%	11.9%	3.5%	3.5%	5.4%	43.6%

1.6: Parent and toddler groups attended (106 responses)

Parents had attended a wide variety of parent and toddler groups with their children, as shown in the Table 3 below.

Table 3: Type and frequency of parent and toddler groups attended

Type of group	Attended once but did not return	Attended regularly for a few weeks or months	Attended regularly for 12 months or more	Attended infrequently as and when	Avoided groups like this deliberately	Had no interest in groups like this	Did not attend groups like this due to time and/or cost

							constraints
General parent and toddler groups	11.1%	19.2%	21.1%	15.9%	16.3%	3.4%	11.1%
Musical parent and toddler groups	5.5%	17.4%	14.9%	11.4%	16.9%	11.9%	21.9%
Arts based toddler groups	5.9%	5.9%	4.8%	12.2%	16%	23.4%	31.9%
Swimming parent and toddler groups	4.5%	16%	17.5%	8%	17.5%	7.5%	29%
Gym based parent and toddler groups	3.1%	6.7%	11.4%	6.2%	18.1%	21.1%	33.2%

However, a proportion of parents did not attend parent and toddler groups due to non-availability of them, time and / or cost constraints as explained below:

There are not many accessible parent and child groups locally, two that I know of and getting there on public transport wasn't easy and cost a lot.

The types of groups I want to attend are not available; I want to meet with mums of prem babies

Table 4: General comments about parent and toddler groups

Reasons for non-attendance	
Baby's illness or disability/health concerns prevented attendance	60
Attended but other parents didn't understand premature birth	20
The groups available were not developmentally appropriate for children born prematurely	18
The groups available were not suitable for multiples	12
Maternal depression prevented attendance	8
Difficult to fit in with working parents	8
Lack of access to groups in the area	7

Cost was prohibitive	7
Told by health professionals to avoid because of child's health	5
Benefits of attending	
Very beneficial	2

For a significant proportion of parents (60) parents, non-attendance at these groups was related to their child's ongoing health problems and / or advice from health professionals to avoid group social situations:

My daughter came home on oxygen and is high risk for infection, so we avoid groups of people/ children wherever possible.

Wanted to attend more groups but we could not afford the groups and I was worried about attending the free ones due to the numbers and illnesses.

This sometimes had the effect of isolating parents:

We were told to avoid mixing with groups of people particularly children as my daughter has chronic lung disease and needed to avoid RSV. This was necessary advice as when she caught RSV as an older baby she was very unwell. It did however contribute to the isolation associated with having a premature and unwell baby.

A number of parents (38) reported that they had not attended parent and toddler groups because they felt judged either by staff or other parents due to their child's small size and / or any developmental delays. Even when this wasn't the case, they felt internal pressure for their child to be at the same stage as other children or they felt that they couldn't share common stories about birth and neonatal care as their experience had been significantly different.

I didn't have much money so couldn't pay up front for a term of sessions. I was fed up with going over my story, feeling inadequate about the birth and sensitive about him being so small

I felt that I had nothing in common with people as their babies were all at different developmental stages, I had to explain my situation to everyone when asked, my baby was on formula and medication and had bad reflux, which meant going out and feeding was hard as people often stared and preparation was difficult.

I found that other mums could make me feel like my baby was in some ways behind which made me feel inadequate. At 1 year my daughter was neither crawling nor walking and I felt that other mums could be judgmental about that, with no appreciation of my daughter's adjusted age. Her gross motor skills are not as strong as many babies of her age, but in all other areas she is meeting milestones. I find it tough that there are comparisons drawn, and I don't feel comfortable explaining that you should adjust her age by 1 month as it feels like I'm being overly anxious

For parents of twins, the practical considerations of having two babies presented particular problems:

Many groups difficult with twins - i.e. swimming, also nerve wracking if older children as I worried about my babies being bumped! Best group was in a friendly church hall when someone saw me come in and said 'mum with twins take the babies and get her a cup of tea!' They had a separate safe area for babies to play/be floor based which was good.

Some parents mentioned other types of parent and toddler groups that they had found useful (described in Table 4 below) because they were more tailored to their specific needs, were more welcoming or were offering something different to mainstream parent and toddler groups mentioned above.

Table 5: Other types of toddler groups

Type of parent and toddler group	Number of parents
Twins/multiple club	6
Premature baby group	5
Baby sensory	5
Breastfeeding support group	4
Local group for neonates	3
Baby massage	3
Groups for children with SEN	2
Music, gym, tumble tots, SCBU, childcare, neonatal patient support group, helping hands, yoga, NICU coffee morning, NCT bumps/babies group, group for PND and PESD, Toy Library, sign language	1 each

1.7: Support from early help professionals (78 responses)

As can be seen from table 6, low numbers of parents had access to early help professionals. However low numbers of parents also state that this would have been helpful. Thirty per cent of parents report that they only saw their health visitor for a short period of time and nearly fourteen percent that they saw them infrequently for a longer period of time. Parents particularly commented that any help given was often too late, for example some parents said they had not seen a health visitor until two weeks after coming home with their baby.

Table 6: Contact with professionals on discharge from hospital

Which professionals have you	Not at all	Not at all but	Once	Regularly for a short	Regularly for upto	Regularly for longer	Regularly for longer	Infrequently for a long time
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seen and how often		would have been helpful		period of time (once a week for three months)	three months	than three months	than a year	
Health visitor	2.4%	0	9.6%	30.3%	13.9%	23.1%	6.7%	13.9%
Social worker	94.7%	1%	2.4%	1.4%	0	0	0	0.5%
Portage worker	92.2%	0	2%	1.5%	0.5%	2%	2%	0
Community neonatal team member	36.7%	10.1%	7.7%	24.2%	7.2%	9.7%	3.4%	1%
Speech and language therapist	64.3%	4.3%	10.1%	3.4%	4.3%	3.4%	5.8%	4.3%
Developmental care specialist	62.3%	8.2%	5.8%	0	2.9%	4.3%	6.3%	10.1%
Occupational therapist	72.9%	4.8%	5.8%	1.4%	1.9%	2.9%	3.9%	6.3%
Play therapist	86.4%	8.7%	1.5%	1%	0.5%	1.5%	0	0.5%
Physiotherapist	60.7%	3.4%	6.3%	1%	4.9%	7.8%	10.7%	5.3%
Dietician	55.1%	6.8%	9.2%	4.3%	3.9%	6.8%	5.8%	8.2%
Early support worker	90.3%	5.8%	0.5%	0.5%	1%	0.5%	1%	0.5%
Child and adolescent mental health services	91.8%	5.8%	0.5%	0	0.5%	0.5%	0.5%	0.5%
Charities such as home start	92.2%	2.9%	1.9%	1.5%	0	1%	0.5%	0

Eighteen parents said that they had excellent support from a range of professionals as shown below:

Excellent support from:

Health Visitors

4 parents

Physiotherapists	4 parents
Occupational Therapist, SCBU, Midwife, NICU Nurse	1 parent each
Outreach Nurse, Portage Worker, Homestart Volunteer	

Ineffective support from:

Health Visitors	19 parents
SLT	2 parents
NICU community support team	1 parent

Nineteen parents said that Health Visitors had insufficient knowledge about premature birth, one parent made a similar comment about the NICU community support team and twenty four parents commented on a fragmented early help system upon discharge from hospital as shown above in the section on comments about leaving hospital and shown emphasised in the comments below:

I have had to struggle to get my son assessed for support as he has some kind of learning difficulties linked to inattentiveness and possible attention deficit. Finally have an appointment with CAMHS which I have pushed for since reception class

My baby struggled with his development and I was worried. Limited to no support offered. Child development worker was supposed to see us every three months. Due to numbers this was not possible so we have only had one appointment so far. Health visitors were not helpful; they had a lack of knowledge and often upset me by giving me wrong information. I feel that my baby needed more support with access to free specialised groups to help with his development and to support and give me ideas. We feel very alone and trying our best to help him. We use the Internet a lot.

I was 645g at birth; she is now 8 years old and academically at the top of her class. She has problems with severe reflux/poor weight gain and asthma. She has attended speech and language, physio, gastroenterology and ear nose & throat. In her first year of life we had in excess of 150 appointments with professionals and yet; most of these appointments were unhelpful. She is where she is in part from luck, but mostly out of sheer determination since the day she was dragged into this world too early. I myself have suffered from PTSD from her birth and the year/s that followed. I had no support for my own physical or mental health and it still affects me to this day.

It was my church who provided all the support - loads of help with housework, meals, laundry, etc., respite care, and, during the school holidays a physiotherapist in the church trained up some church members who formed a rota and came round every day to do my daughter's physiotherapy exercises with her

The neonatal team just came to check weight but didn't give any advice and just made me feel inadequate. I was left alone after this as health visitor only

came once. I went from being in hospital not being able to touch my baby to going home on my own feeling like I couldn't cope. The only person I got advice from was the breastfeeding woman at the support group I went to once a week.

Health visitors came and only once asked how I was coping. I burst into tears and said I was struggling as nothing had gone how I expected and it was hard having a baby who needed oxygen and a ton of medication. She told me it was "probably just baby blues" and that it would pass...

The health visitor made me very stressed about my daughter's poor weight gain. I saw her weekly for several months and felt like I was put under a lot of pressure (including pressure to stop breastfeeding) because of a problem with weight gain which turned out to be the result of a PDA. In all my interactions with health visitors I feel they lack basic understanding of prematurity - e.g. Not knowing how long to correct premature babies' ages. Almost every parent of a premature baby I've spoken to say the same thing. I found physio difficult to get but really useful. The dietician was briefly very useful and reassuring.

The health visitor was judgemental, had no idea what she was talking about and generally unhelpful. The OT and ST were helpful but we didn't see them often enough. The physiotherapist was a lifeline. We had 11 social workers in 10 years because of staff retention problems in our area, and only one of them was any good.

One parent particularly commented on how fragmented services were:

We had too many cooks! There was no-one over-seeing the overall picture. Often professionals in the community didn't get involved as they felt we were being seen by 'specialists'. In reality hospital appointments were often nothing more than a weight check, tell me I needed to make her eat more but with no tangible support or consistency. Not meeting a consultant, not seeing the same Doctor twice. Now at age 8 we have finally been referred to a Paediatrician who is looking at her health as an overall picture and finally feel we are getting the medical support we should have had all along.

However, one parent commented that when early intervention is provided, the benefits and outcomes can be quite significant:

Our son has had specialist child psychotherapy for children 'at risk of autism'. He doesn't have autism and I believe the early intervention he received has led to this. He was the surviving twin. His sister died at birth

Parents made a range of comments about early help / support generally as shown in Table 7

Table 7: General comments about professionals early on

Comments about early help services	
Insufficient Early Childhood Intervention	10
Disintegrated services	2
No support upon discharge	5
Support not long enough	4
Appointments frequently cancelled	1
Had to wait years for assessment	1
Used the internet a lot	1

1.8: Pre-school education and starting school

143 (68%) of children reported on are attending pre-school education. The type of setting attended varied with ages of children. As might be expected, the number of children attending mainstream provision decreased incrementally with age as any difficulties and delays in development became more apparent. Higher numbers of children were attending specialist or combined settings as children matured.

Table 8: Types of setting children typically attend

Type of setting	Age range				
	0-12 months (only 42 children this age attending pre-school)	12-24 months (63 children this age attending pre-school)	24-36 months (74 children this age attending pre-school)	36-48 months (80 children this age attending pre-school)	48-60 months (51 children this age attending pre-school)
Pre-school within a mainstream setting	93%	94%	93%	85%	80%
Pre-school within a specialist setting	5%	5%	6%	13%	0%
Combined early care and education	3%	2%	1%	3%	20%

The majority of parents (99%) were able to send their child to the pre-school of their choice. For those that were not the reasons were due to location of home / location of pre-school services (rural home location with no access to a childminder which was the parent's choice) or due to parental choice being in another county which the LA would not fund. 17.5% of parents changed their preference of pre-school education when their child was born prematurely. The reasons for this were varied:

Table 9: Characteristics of pre-school education choices

Physical structures and processes	
Chose a small setting	8
Chose a specialist setting	2
Chose a setting that could support child's health needs/child's support worker	2
Social structures and processes	
Chose a setting with higher adult-to child ratios	8
Chose a setting with staff who were experienced in supporting children born prematurely/children with SEN	7
Chose a setting who offered developmentally appropriate practice	2
Other	
Child started earlier due to funding given	2
Mother/child stayed at home due to child's health needs	1
Delayed pre-school entry to allow home care for longer	1
Child remained in pre-school for longer (delayed school entry)	1
Chose full day care to save money and setting with outstanding OFSTED report	1

For one mother, her child's premature birth impacted on her own employment status and career opportunities and in the longer time, the family's financial situation:

Originally I was planning on putting my baby in nursery from 9 months but because she wasn't strong enough I had to quit my job to stay home with her. I then had to find a job when she was 20months as I had used all savings. She has been ill more than she has been in nursery since.

1.8.1 Informing pre-school staff about premature birth (out of 143 responses)

The majority (83%) of parents volunteered the information that their child was born prematurely to pre-school staff, whilst another 7% were asked specifically about preterm birth by staff. 7% of parents neither volunteered nor were asked, 3% didn't consider it important for pre-school staff to know and pre-school staff didn't ask.

However, only 49.7% of staff subsequently asked about any developmental delays/difficulties resulting from premature birth. For those that did 23 knew on admission, 25 asked as part of general settling in questions, four asked in response to their own observations of the child, one asked in response to information given by parents and one parent reported that early years practitioners didn't ask but the parent felt they should have done so.

For those professionals that did not ask, the majority of parents (65 out of 71) thought that this was because staff were not knowledgeable about developmental risk related to premature birth, whilst the remainder thought they had not asked because the child appeared to be developing appropriately for their age or for one parent because the child attended the same setting as the parent's workplace:

I don't think they have any appreciation of the long term difficulties in education that a premie can experience

They see the child for the child and don't let their premature birth define them.

39.9% of parents reported that the pre-school setting had adapted their strategies to support their child, whilst 44.8% said that this was not necessary and the remainder reporting that the setting had not attempted to adapt their strategies at all even though this would have benefited their child developmentally.

1.8.2 Training for early years professionals

Parents would like early years professionals to receive training about premature birth as shown below:

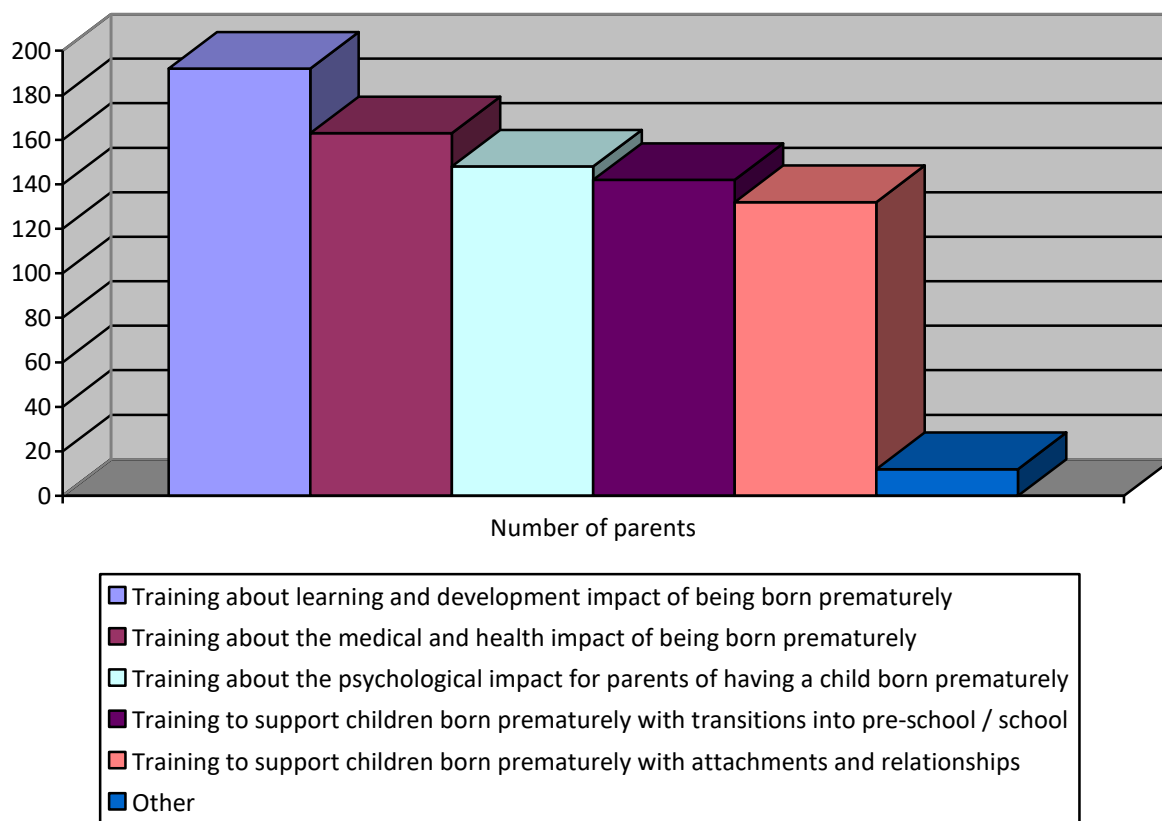


Figure 5: Training for early years practitioners

Some parents commented on basic aspects of early years provision such as equipment or settling in procedures that would serve as a physical or emotional barrier to their child's inclusion at a setting:

[Early Years Practitioners need] Information specifically regarding the placement and accessibility of age appropriate toys and equipment. My daughter is due to start nursery in a couple of weeks at 11mths old. However although her mental and cognitive development is correct for her age, physically she is the size of an average 5mth old. Looking round the nursery we found that the tables/chairs where she would be expected to eat/play are far too high and some of the toys and equipment will be out of her reach

My child wouldn't separate from me. He was terrified. The specialist nursery had an entirely behavioural approach and wanted to rip him from me and let him cry it out. I was not going to re traumatise him so refused. They told me he would get worse (developmentally and re attachments) I disagreed strongly and found a child minder who was patient and kind. She let me manage the separation slowly and thoughtfully. Now my son separates and transitions with confidence and he trusts me!!!!

Whilst one parent felt that training about prematurity was not necessary as practitioners should support individual children based on their own observations, other parents would like practitioners to be knowledgeable about the following aspects:

- Child development/developmentally appropriate practice
- How to use specialist equipment (Nasogastric Intubation and Feeding)
- Understanding parents' concerns
- Deafness arising from prematurity
- Disability arising from prematurity
- How to support siblings of babies born prematurely
- How to support children / families where there are multiple births associated with prematurity
- Appropriate physical activities for children born prematurely
- Understanding of the concept of 'corrected age'

A couple of parents would like early years practitioners to be knowledgeable about the impact of multiple births:

Possibly something also linked to multiple birth, for example certain issues around behaviour and helpful ways to support the twin/multiple dynamic

Sending my twins to private nursery at approx 10 months corrected age, when I returned to work was a bad decision. One in particular became very anxious. I tried to find a childminder as I thought that might improve things but couldn't. Luckily we were able to take them out after a period of time (9 months) and saw an immediate improvement in their confidence in all areas. I'm aware of some attachment and MH issues related to prematurity and would advise parents not to ignore these issues. If the child is unhappy, take them out, despite the fact that we're always told 'just go, they're fine once you've left' etc.

1.8.3 Delaying school entry (139 responses)

Only 11.5% of parents were given information about delaying/deferring school entry for their child. Of these 9 were delaying, 12 were not and 2 were unsure.

Eighty two parents would have liked more information about delaying school entry, 31 said they didn't want this kind of information and 21 said they were not sure or it was not applicable to them. In terms of giving advice to other parents about delaying school entry, the following comments were made.

Table 12: Advice you would give to other parents about delaying school entry

In deciding whether to or not	
Follow your instincts	16
Don't feel pressured about developmental milestones	12
Early years care and education was good for promoting social skills/socialisation	11

Ask lots of questions	9
No need to delay	8
Find specialised prematurity groups to avoid your child being compared to typical children	7
Intervene early	6
Home educate instead, school system doesn't understand premature birth	4
Due date is the best predictor	4
Development improved on entry to school	4
Pre-school was a disaster	4
Delaying entry was very beneficial	4
No choice as mother had to work	2
In choosing the school	
Find out how the school will adapt to suit your child/choose the right school/smaller setting	12
Give professionals as much information on your child as possible	4
Develop good relationships with professionals in the school	3

For our child, sending him to nursery was the best decision we made – I don't believe he would have developed as fast or been ready for school had we had him at home only. He is an only child and the interaction with other children was also important in our opinion

I would advise them to defer or delay entry into school and to be insistent with nursery school staff when they feel something's not quite right but they're being told everything is "normal".

Had I known I could defer or delay his entry into school, I certainly would have done so. I feel he is under too much pressure to perform in the same way his peers do and he gets frustrated and angry when he can't do what they can.

I am delaying my twins. I was lucky to find out about it through other channels. To me, where premature children are born into the year above it should be virtually expected that they start school in line with their due date. This is not our position but I still feel my boys will benefit greatly from an extra year to develop social and emotional resilience.

It was the right thing to do for our daughters and all professionals we spoke to were very supportive of our wish to delay their school entry. I do feel that more information should be available to parents regarding it and that schools/head teachers/admissions authorities need to be more aware of it and

more supportive. We were lucky in that I work in education and am aware of the admissions code and our rights. Not all parents are.

1.8.4 Child's experience of starting school/attending school (43 responses)

Parents reported that only 15.6% of teachers/teaching assistants asked about premature birth on entry to primary school. 77% of parents informed teachers/teaching assistants themselves. Whilst this might appear unproblematic, only 34% of teachers and teaching assistants were reported by parents to adapt the environment or their teaching strategies to support a child born prematurely and 61% of parents feel that their child needs additional support and/or resources at school.

Table 10: Teachers understanding and awareness of premature birth,

Teachers and teaching assistants	Agree	Strongly agree	Disagree	Strongly disagree
Knew that my child was born prematurely because they asked	10%	5.6%	34.4%	50%
Knew that my child was born prematurely because I told them	25.6%	61.1%	10%	3.3%
Were aware of the socio-emotional needs of children born prematurely	8.9%	5.7%	41.1%	43.3%
Were aware that prematurity presents a risk for delays and difficulties in learning and development	37.5%	5.7%	22.7%	34.1%
Adapted the environment and teaching strategies to support my child	23.9%	10.2%	39.8%	26.1%

Teachers don't understand the impact being born prematurely has on a child, so you have to explain it to them. You need to find a school where you feel you will be listened to, and your child will be supported.

The total lack of understanding in the local primary school was incredibly traumatic for us as a family and damaged our son's development even further. Educators must be taught what the impact of prematurity can have

During my sons first year at school I raised my concerns about him needing more help and struggling with things but the teachers reaction was just to brush it off with a comment of 'Oh he's fine'. He's now in year one and his teacher completely agrees with my concerns and is helping me as much as she can with getting him extra help. Have to say I think this is because she's an older more experienced teacher

We picked the primary school based on their community relations and soft approach to beginning school in reception. School days were built up gradually over a period of a month and the class sizes are relatively small compared to other schools in the area. All of these helped my son to settle in without being overwhelmed.

My son had an EHCP to ensure the most suitable school. The school were very understanding & supportive but I believe this is down to having picked the right school setting & me engaging with them early on

In the main my daughter's school has been good. One thing that is a continuing problem is that she is small for her age and so needs to use a step and toilet seat adapter to help her when going to the loo. This means that not only is she having to think more about when she needs to go, but makes her stick out amongst her classmates and could be a potential source of bullying later on.

Table 11: General comments in relation to starting school (110 responses)

Nineteen parents said that teachers didn't understand premature birth or were slow to respond to parents concerns about their child's development and learning. By contrast 12 parents said that their child's academic skills are fine and another nine that the response of teachers and teaching assistants to children's difficulties and parents concerns was overall very positive.

Teachers in school didn't understand premature birth – slow to respond to parents' concerns	19
Academic skills are fine	12
Response of school staff was positive	9
Socio-emotional skills needed support	9
Statement in place on entry to school helped	4
Despite being youngest in class, child thrived	2
Move to private school due to poor state school response	2
Home schooling worked better	2
Child had multiple problems that were only evident on entry to school	1

Table 13: General comments – overall (76 participants filled this in)

A number of parents reported that their child had long term health conditions and / or special educational needs and disabilities:

"[He has] Severe and several allergies, asthma, hyper mobility, developmental co-ordination disorder, sensory processing difficulties, social difficulties. The children do very well on a day to day basis considering all this. As parents we have very little understanding of social and emotional problems associated with pre term babies and don't know where to look for help and support with this. There also seems very little help and support available for parents as children grow up. Any advice or further information would be very much appreciated ". (Parent of Twins born in 2010 at 28 weeks (very preterm)

My child has been assessed as having slow processing speed and suspected Aspergers, my other premature child has SPLD's including dyslexia, dyspraxia, dysgraphia and ADHD. Was born with shallow hip sockets and talipes. Both are now flourishing educationally and socially now they are being home educated and have the support they need and deserve. Just a shame the NHS and schools wouldn't provide it.

These are shown further in Table 12 below, although it is not known whether these are confirmed diagnoses.

Comments about development/SEN – parents reported that their child:	No of parents
Has long term health problems	9
Has sensory impairment	7
Has Dyspraxia	4
Has Autism Spectrum Disorder (ASD)	4
Has Cerebral Palsy	4
Has Attention Deficit Hyperactivity Disorder (ADHD)	3
Has Dyslexia	3
Has Sensory Processing Disorder (SPD)	3
Has verbal dyspraxia	2
Has Development Co-ordination Disorder (DCD)	2
Has attachment difficulties	2
Remains small for age	2
Has Dysgraphia	1
Has Celiac disease	1
Has Apnoea	3
Gastroesophageal reflux disease (GERD), Hyperspaida, Microphthamlia, hydrocephalus.	1 each

By contrast, seven parents stated that their child's development meets with or exceeds the Government national average expectations for children of the same age.

Part 2: Interview findings

Analysis of interviews highlighted themes of....

2.1 Hospital experience:

Two parents mentioned that they would have liked the risk of prematurity to have been discussed prior to the birth. They talked about being unprepared for the eventuality.

I don't know. It's very hard, isn't it, because you think...it is such a scary time when it happens? I knew nothing about premature babies beforehand. No-one had...like none of the midwives had even mentioned it. You're not even given inkling that it might be a possibility. You really are just thrown into this world or things that just seem so farfetched. It is a real shock to the system.

One of these parents also said that she would like more research into the reasons for prematurity as no-one had explained to her why her children had been born prematurely.

2.1.1 Information given to parents

Whilst three parents said that they had received enough information about their child's long term developmental outcomes, the remaining ten parents felt there was an absence of information given to them in hospital about this. They said that information given to them focused on their child's immediate survival and health care needs. One father described the choices he and his wife were faced with when her waters broke at 23 weeks and 2 days:

So we then had the chat with them where they talk you through the likely outcomes which are under 24 weeks you've got two choices, you can either cuddle them as they pass away when they're born or they can give them a very quick medical assessment, but then it may be that they die before that so you don't get to cuddle them while they're alive, but you have to choose one of those two things which is quite a conversation. They also talked then about the reasons for that, that sort of below 24 weeks the likelihood of developmental issues, and that was based on the EPICure 2 Study which I know is – well, actually, for survival rates now is a little out of date, but as far as actual developmental it's still fairly accurate I believe, isn't it, in the short-term, as far as likely outcomes. I went away from that and spent some time, I went away and read the EPICure 2, did more research on that to get understanding. We were between NICU, HDU and special care we were there four months in total, so this was during the period of that time I went away and read it. As far as actual specifically the doctors or the nurses talking to us about potential developmental delays, not massively, no. It was mentioned occasionally and we did get referred to a developmental specialist as well who's seen her a couple of times now and basically said she doesn't need to see her anymore because everything is fine, but she's kept her on the books, Charlotte, just in case something happened and rather than having to re-refer, we can just jump straight back in.

On balance he felt that the amount of information provided was appropriate but admitted that this depends on individual circumstances. He suggested that his wife probably could not have embraced any more information and was content to monitor her daughter's progress by observation, whereas he needed more information so that he could react. He valued the honesty at the beginning of his daughter's journey regarding the choices available to him.

For the three parents who reported having ample information, their child had been at risk of dying. One parent expanded on this aspect by explaining that her child had experienced bleeds on the brain so they were advised about the possibility of developmental delays. However, she also stated that she felt that they were ‘steered away from wanting answers’ in relation to specific examples or details of developmental delays. Some parents commented that there was conflicting information from different health professionals. Another parent reported that the timing of information provided was crucial in determining parent’s ability to absorb the details and ensuring that the information was useful:

I think it would have been useful to know more when he was out of danger, when they were preparing to move him, when he was more stable and they were moving him to the next ward. So when you’ve gone from NICU which is obviously really intense and you can’t really focus on anything because it’s just such a horrible experience.

This parent also described the shock of being informed about her son’s discharge following four months of hospital confinement because no one had explained what would happen next. Although she was given sufficient information about lifesaving and resuscitation procedures, there was no discussion about long-term developmental outcomes.

One parent who works in child protection said that she was surprised there had not been any ‘case style’ multi-agency meetings for parents to discuss their child’s progress with professionals as she would have found this useful.

Memory boxes were mentioned by three parents as being useful and important in terms of receiving information about their child on one hand, but they were a source of alarm and upset on the other. They were reported to encourage parents to be practical and make difficult decisions about which memorabilia to store in them, but also inject a dose of reality into an already stressful situation as parents are encouraged to envisage a worst case scenario where the memory box may be the only reminder of their child should they not survive:

The memory box was always in his room on the trolley where all of his bits and pieces for washing him and that were and all his medical...like the cannulas and things were kept – on purpose we didn’t look at the memory box until he was starting to improve and it was looking like he was getting better. I didn’t want to look in the memory box up until then, because I didn’t want to know...I remember the nurse opening it and showing me all of the different bits in it, showing me all the different leaflets and things, and I remember there being a leaflet about death, which is a part of the ward, I get that, but we consciously didn’t want to look in the memory box until we knew that it wouldn’t just be a memory box because we weren’t going to have George. You know, there’s two reasons, isn’t there, why they do a memory box, we didn’t want to have the negative reason for that memory box.

One father described the strong contrast in information and the number of adults available between NICU and the following wards. Also he commented on the lack of information on how the child is doing in terms of how outcomes are graded. One mother said that sometimes she felt that health professionals did not disclose information that she would have liked to have known about such as one her twins had a bleed and it she had only discovered later on

that this could lead to serious complications which she would have liked to have known about at the time. Another parent said she was provided with sufficient information about the possible consequences such as cerebral palsy and developmental delays (interview 7). This had enabled her to prepare and accommodate such as using sign language from a very early age. Information was also useful in terms of knowing how to relate to a prematurely born infant as explained by one mother:

They gave me the Bliss packs and one of those – well, there was a leaflet and there was a section in the booklet about if they don't make it, and I didn't want to go there, I didn't want to go through that. But when he was – well, for J, I remember he was five days old and he'd kind of hit a wall and things were going rapidly downhill and they said, you know, now might be the time to read that. I did actually find that quite helpful because it expressed other parents' views that when their child didn't make it, you kind of had two viewpoints, one was the viewpoint of parents who had kind of held back from developing a bond because they didn't want to get close to a baby that wasn't going to make it, and I related to that. But the experiences in the booklet sort of showed that actually in both cases the baby didn't survive, the ones who didn't develop the bond felt guilty because they wondered if maybe that had an impact on the baby, but the ones that did develop the bond said that there was kind of a sense of satisfaction that they knew that the baby knew he was loved and that sort of thing. So it did help me to just drop that wall a little bit because I found it very difficult to sort of let myself fall hopelessly in love with him because I didn't know, I wasn't sure and I didn't want to get too attached.

2.2 Coming home:

2.2.1 Professional support/professional practice:

Follow up information (who to contact should there be any concerns on leaving hospital) was reported as being extremely important by all parents and yet reported as being absent from their discharge plan. One parent commented on fragmented services and the lack of understanding by GPs about the developmental delays that can result from premature birth:

I went to my GP about his speech and language, so he's now seeing a therapist. But the GP referred us for a development assessment and that got mixed up. The consultant at the hospital wasn't geared up to do the assessment and referred us somewhere else, but now the health visitor has to come out and then apparently it all has to start again.

It makes me really angry. So annoyed. Because it's like, well, if you had a tube stuck down your throat for 46 days or whatever it was, if you'd seen him turn blue when he was tried to give a bottle and nearly had to be resuscitated every single time he was given milk, just seen what he's been through, the amount of blood transfusions and stuff, I'm not surprised he's behind. And I don't understand why they think because he spent four months in an incubator, basically, which should have been four months in my womb, why they think those four months...they're just going to catch up. It's like he shouldn't have been born, he should have been developing for those four months, so if he was

inside me growing you wouldn't say he should have caught up. It's like he was in an incubator doing nothing, so why do those four months all of a sudden count and he was learning and stuff when he wasn't, if you know what I mean. He had a thing draped over him most of the time.

I already felt like I'd failed J in the worst way because I hadn't even carried him to term, which is the most basic of things that a mum does. And then to be told you've automatically been assigned a social worker, in my mind a social worker is for bad parents, so it validated those feelings of guilt. So then that built, so then when he came home and I was finding it difficult just to cope with everyday things like going out of the house and things, instead of recognising that they were symptoms of the postnatal depression, I viewed them as more things that I was failing at. And as I say, the guilt then...the guilt and the fear fed each other, and the fear that he was going to get taken away from me, that I was going to lose him, I've never really recovered from that fear that I was going to lose him. It became, he's going to get taken away from me, as opposed to, and he's going to die. (interview 8)

One parent (parent 13) reported positive experiences of the community paediatric team on discharge. Two parents mentioned that communication between the Hospital and the Health Visiting was poor. Nine out of thirteen parents reported negative experiences of the Health visiting service, with two parents expressing concerns that that the service focus on the child rather than the whole family / parents.

Health visitors were the least helpful. They were the worst. They just say stupid things to you like can he hold his head up, can he sit up yet, and I'm like, well, he shouldn't have been born yet. That's a really stupid thing to say, things like that. I found them really unhelpful.

The health visitor was awful, hadn't got a clue what advice to give us and everything like that at all, frankly was about to retire and I think had just switched off completely. But then the next one who she passed on to wasn't much better as well. That is slightly related to the fact they don't have any training in this aspect, health visitors aren't really generally trained in any of these sort of developmental issues, so until my mum went through this experience with us, we wouldn't have really realised how to refer to a development specialist.

One parent said that the HV visited before her child had been discharged and on finding that the child was still in hospital then didn't visit again until a month later when the baby was discharged. She expressed her disappointment that they hadn't acknowledged her need as a mum for emotional support and health guidance.

By contrast four parents expressed positive experiences of the Health Visiting service.

prematurity, telling me when would be the right time to take George out for some fresh air in the pram and things like that, like keep him in for another few weeks yet because he's not due yet so don't take him out in the fresh air just yet and things like that. When I used to take him to the baby clinic when it

was weaning time she gave me a Bliss weaning leaflet because that was for premature babies essentially, so just to give me some extra guidance. She was totally tuned in with having a premature baby, and it was an amazing experience, I could ask her anything, I could ask all of my concerns. She did bring up a bit about postnatal depression because I'd had that with my daughter and obviously the medical profession were concerned with the amount of stress after having George that that was going to happen again, so I automatically went on antidepressants as soon as I had him because I wasn't going to be breastfeeding and she was conscious of that and asking me how I was in myself and everything, I had a brilliant experience with the health visitor.

I've been very lucky, I've had a very lovely health visitor who had to come to the house because of the risk of infection but she hasn't complained about that.

We had an excellent health visitor, she did a lot of extra, we were out of reach of the neonatal outreach team, because we live in the middle of nowhere, so she took on a lot of I think what they would have done normally and visited more often and things like that, did extra weighing and things like that, kept a good eye on us really

We saw the same health visitor for the first three weeks when she came round to the house, and she was very good. I didn't feel that she was necessarily particularly trained in premature birth, but I didn't feel that she wasn't either, if you know what I mean. She seemed very good. But after that there was just a wait and we saw various health visitors, and I felt that perhaps there as well there wasn't always the same understanding.

2.2.2 Emotional aspects of coming home for parents:

Ten parents described their experience of pregnancy and starting a family in terms of being 'a different experience to other parents.' Some expanded on this, saying:

What I experienced was 'a different kind of normal' to other parents.

Another parent expanded on this saying that she had to learn to love her son 'in a different way' due to the emotional detachment she experienced arising from being separated from him during his early infancy and feeling as if he were being cared for by other people.

Five parents (mothers) described experiences of post-traumatic stress disorder (PTSD) which sometimes hadn't been diagnosed until their child attend compulsory education when they had sought professional counselling. There were many descriptions of loneliness and isolation resulting from enforced confinement in the home. Treatment for this sometimes came from Counselling services provided by charities such as BLISS and sometimes from specialist services. Although some parents sought support early (2 parents) others either didn't seek treatment or didn't receive it their child attended compulsory education by which time their PTSD was severe. One parent mentioned highly specialised treatment such as Attachment Parenting and (EMDR) provided by the Improving Access to Psychological Therapies Service:

Eye Movement Desensitisation Reaction is a trauma therapy where, the way they described it to me was, when something traumatic happens, in your life, and at the time it's too traumatic to deal with, or its ongoing and you never get a chance to sit and take stock of it, one of the analogies they use is like it's emptying a filing cabinet into the middle of a room, it all just happens, everything's in a big pile. Usually your brain would file it all away in date order, and time order, with a little date stamp on, and the memories that make you sad would make you feel sad, but it would still be in context of it having happened. You don't actually experience it anymore, but you look back and think, oh that wasn't very nice. Whereas with post traumatic stress, because it's just in this massive pile, it's in the wrong part of your brain, and any time something triggers it, she said to me, it's like tripping up over the pile again, any time something triggers those same reactions again, you have all the same physical reactions instead of just remembering that this is how it felt and it wasn't very nice, you end up feeling it all again, so you get the sweaty palms, the racing heart, the anxiety, you have the physical reaction of actually being back there and it happening again.

Others discussed the difficulty of being a health professional as well as a parent experiencing the National Health Service in these circumstances.

I think as a Paramedic I was stuck between two worlds of not knowing very much about premature babies and not being able to wait for technical information, but knowing enough to be worried about it, so I preferred to be told more.

By contrast two parents described the benefit of this dual identity as she felt that she had the knowledge and means to access information and support that she otherwise would not have known about.

A couple of parents had experienced isolation and loneliness when they left hospital and emphasised the need for professional support in the very early days of coming home. They felt that the support provided had been less than they had expected (for example not seeing the Health Visitor or anyone else in the week following discharge just to check that everything was OK, had been a surprise).

Marital breakdown resulting from the stress and strain on relationships was reported by two parents

We ended up getting divorced about a year after, 18 months after Jack was born, he just said, well he waited until I got to the point where I wasn't on the brink of not being able to cope any more, I'd had all this counselling from BLISS, got back to work, started to be a bit more normal, and he just lost the plot. He just said, I thought you were going to die, I thought he was going to die. Nobody gave him any time; nobody asked him how he was doing. Because I was in the hospital with our son everyone was just, how's your wife, how's your son? Nobody had any thought for the fact that he was still working full time. Because you've suddenly got that, right, well he's the only earner, there's two weeks of parental leave that they get but what's the point in taking

it while your baby's on the neonatal unit, because you can't really do anything anyway? So, I was in Special Care, J was in Special Care day to day, we would hope he would be okay, but we would see how he was doing, and poor S there doing all my washing, all the shopping for food and what not. He'd go to work, come home, go home and grab the dry clothes, go to Asda on the way, bring me some food in, we'd eat together, he'd spend the entire evening sat with me and our son So I'd only probably see him for three hours a day. He went home, put more washing on, went to bed, got up, you know, and it was just Groundhog Day for him, for the month that I was in hospital.

So, I didn't go home from hospital until 18 days after I'd had J. So he'd got all of that, and he just fell to bits 18 months later, and just said, I can't do it anymore. So, he had a breakdown, and left with a 19 year old (interview 5)

2.2.3 Family Support:

For eight parents, there was ample family support in terms of practical and emotional support for the parents. For example, providing pre-cooked meals and visiting as often as possible. However, four parents had family who lived too far away to provide any practical support and others felt that wider family members had little understanding of what kind of support might be needed in the circumstances or were hesitant to offer for example baby-sitting services as they were nervous about caring for a premature infant and / or multiples:

Well, because we were in hospital for such a long time, and they weren't allowed to visit. So that time was really awkward. Even my mum and dad were only allowed to visit at certain times. Then we came home and we were obviously really paranoid about germs, so we didn't want anyone to come and visit. And then you get really isolated as well, because I didn't go out when I came home. The health visitor came to my house, because I refused to go to the clinic. But, yeah, I just didn't take him out. Obviously the normal things you do go out with your mates and go and have coffee and go to soft play areas and all those sort of places that are just riddled with germs. I don't think we went out for a year, for the six months at home.

By contrast, one parent mentioned that as a family they just wanted to be left in peace following intensive intervention during their hospital stay, saying that they just wanted to “kind of hideaway and it just be the two of us or three of us when my husband was around.”

One parent mentioned the importance of paternity leave for fathers explaining that her husband's employers had been flexible in terms of his working patterns which had made her coming home experience manageable.

An equal number of parents (three each) had some support from friends or no support from friends, whilst the remainder of parents didn't mention support from friends at all.

2.2.4 Charities:

A number of parents (eight) mentioned the important role played by Charities in both hospital and home support. This included BLISS charity for children born sick or premature, Tommies and Homestart.

2.2.5 Peer support

A number of parents (three) stressed the role of parent to parent support in that other parents who had shared similar experiences provided a degree of 'comfort'. By contrast parents who didn't have similar experiences could be a source of stress as they were more likely to judge children's development unfairly. One parent mentioned that she had tried to organise a support group in her area for which she had support from her local MP but this had not materialised as she needed another parent volunteer to do this with her and hadn't managed to find one.

2.3 Special educational needs and disabilities

Parents talked about their child's long-term health concerns and special educational needs

For children, parents reported on long-term consequences of pre-term birth in terms of development. Not all children had developmental delays and one parent reported positive aspects of development, despite her having read extensive literature regarding developmental delays and academic problems. The same parent felt that his wife's knowledge as a childcare assistant had contributed to this.

One parent reported delays in hygiene routine training (child still has toilet accidents and is still wet overnight at the age of 7). In addition, this child has autism and renal dysplasia. One parent said that although her child did not have any developmental delays he had ongoing chest problems which resulted in missed school time due to sickness associated with colds.

One child had developmental delays associated with autism, social communication difficulties and hygiene routines (toilet training delayed beyond pre-school stage). Another had chronic lung disease and is oxygen dependent at home (concentrator at home and tank outside the house). This child had a twin who died prenatally due to twin to twin transfusion syndrome. One child is 'susceptible to lung problems' and has been hospitalised twice for serious chest infections. Another child had been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and is socially immature and has memory impairment that requires extra support at school.

2.4 Pre-school education

2.3.1 Parent and toddler groups

Nine parents had attended parent and toddler groups although a couple of parents had delayed this until their child was 18 weeks old for one and 12 months old for the other due to health concerns or the difficulty of leaving the house for the other. For parents who hadn't attended these groups, one mentioned the practical difficulties in attending parent and toddler groups with twins, whilst others said that they had not been able to attend due to the high cost of such groups. Others said they didn't attend such groups because their child was not developmentally ready (either smaller than their peers, unstable in terms of balance / walking or not physically robust enough or healthy enough.) One parent said she had been house bound for five and a half months because her child was oxygen dependent and leaving the house was only possible in short time bursts due to the oxygen running out. Another said she refrained from attending groups because she didn't feel that other parents understood her experiences of trauma (she was audibly upset at this point). Another said she hadn't attended

because she was embarrassed about the medication she had to administer to her son which involved syringes and sachets of medicine and took time to organise. She felt that other parents would not have understood. However she had attended classes at the children's centre where another prem birth mum attended so there was a shared experience (int 6). Another parent reinforced the need for shared experiences and the discomfort of attending groups where this was absent:

I took him to baby massage when he was very young and that was run by the SCBU unit nurses, and it was only open to parents who'd had a preemie so I felt quite comfortable going there because I felt like I was amongst women that had been through what I'd been through. When he was a little bit older I started taking him to Rhymetime sessions at the library. I did it more for him obviously but for myself I found it very uncomfortable, I didn't really enjoy it.

I: Why was that, in what way was it uncomfortable?

R: I think just because you've got lots of...there's a variety of ages because it's open to all children under five, and so you would be overhearing conversations and other parents would try and engage me in conversation and I felt like I didn't belong because I didn't have the same experiences they did. And I felt like I was on the outside looking in, and I still...I don't know, I still struggle to view myself as a mum because I didn't really do the whole pregnancy thing, it was three months before I found out I was pregnant and then I had him at six months, I didn't have a particularly big bump, I hadn't really felt him moving. I certainly hadn't got to that heavy, waddling, can't wait for baby to come, and didn't do any of the nesting, any of the planning. So I kind of found myself occasionally thinking, aw, I wish I could have a baby, and even though I had a baby, but the two weren't the same thing, if that makes sense. (Interview 8)

The parent above went on to describe the kind of service that she would have liked where she could share face to face conversations with other parents who understood her experiences so that on 'difficult days' she had someone to talk to .

Parents commented on the loneliness and isolation that results from the necessary confinement in the home (for health and medical reasons.) One parent (parent 2) said that she paid for home-delivered services such as baby massage (normally delivered in Children's Centres).

Another parent (parent 13) said that they had enjoyed the local parent and toddler group and his wife had made a number of long-term friends through attending their local health-related group (antenatal classes). He said the hardest aspect was how to respond when other parents wanted to touch his daughter which was difficult due to the possible risk of contamination and transfer of germs.

2.4.2 Pre-schools/nurseries/childminders

For those children who had attended pre-school education, eight parents said that teachers were aware that their child was born prematurely, whilst three said that they did not feel it was necessary for teachers to know. For eight parents teachers had adapted their teaching methods, whilst two hadn't and parents didn't feel it was necessary to do so.

One parent (parent 2) described her son's difficulties in a pre-school setting:

He goes to a normal nursery and they're really good, but I don't think he gets involved in the activities as much as the other kids. His attention span isn't great if I'm honest.

Another stressed the importance of communication with pre-school staff to ensure safety and well-being for children born prematurely.

The whole nursery thing was really tough because, as I said, I lived in a bubble for such a long time that when he went to nursery I just found it so difficult because I was so paranoid about germs. You can imagine what it's like, they're all coughing and spluttering and stuff. So that's just really difficult. But I think then you're dealing really with the nurseries and the preschools just to make sure you take time to sit and talk to the school and explain the situation and your concerns and what you've been through. In the end the nursery were really good, they used to phone me up in the morning and tell me if there'd been any outbreaks of any type of issues so that I could make a decision whether I was going to bring him in. I think within the first two weeks of enrolling him they had German measles. So I was like, well, he's not coming in, he hasn't been vaccinated yet. So they were pretty good.

The same parent also stressed the importance of early years staff understanding the impact of premature birth as she had already removed her son from a previous nursery due to lack of understanding from staff and a judgemental attitude to her son's developmental delays. The current pre-school allow her son time to complete tasks and differentiate / personalise activities for him. They also planned a phased transition into the setting which allowed parents to stay for some of the time to assist with settling in. Sensitive settling in was mentioned by another parent:

So the nursery school were brilliant at helping, and it was them that found ways of making him settle more quickly. Because he hated that situation, they always used to take him from me, rather than, 'cause I couldn't have left him playing at anything, he would have just chased me back out again, one of them always came and either picked him up, or took him by the hand, and said, come on, we'll go and wave out of the window with mummy, and then we'll go and do something. So, they were really responsive to his needs in nursery.

Another parent mentioned the lack of understanding from pre-school staff about delayed hygiene routines and the need to support children born prematurely with social pragmatic skills.

Another parent mentioned the importance of pre-school settings determining realistic targets for children born prematurely whilst another talked about the childminder's creative approach

Yeah, I don't think I've come across anybody from, my childminder didn't at the start, but learnt a lot because I told her stuff, and she was very, very adaptive to doing basically what he needed, so I credit a lot of his development to her, 'cause she was really, really good at changing things to suit him. Because, obviously he was stuck on his back until he was about 18 months old and couldn't walk until he was two, his brain wanted to do stuff that his body couldn't do, and he was getting really frustrated. So, she used to be really good at doing lots of sensory play and stuff that kept him engaged, but he didn't really need to be able to walk for

One father said that his daughter's pre-school had been very responsive to their concerns about possible delays and talked at length about how they would accommodate her needs. However, despite this, there was an incident where they had over-estimated her balance resulting in a broken arm. More observations of her gross motors skills have resulted from this.

It was stressed by one parent the importance of staff understanding the emotional impact on parents and how this might affect future pregnancies in terms of anxiety and anticipation of problems:

I think it's very important for them to understand obviously you've had this child that's been near death and actually you probably are slightly over protective and maybe a bit needier than some other parents. You're so grateful that they've made it you don't want anything else to happen to them and while you can protect them when you're with them, obviously giving that responsibility to someone else is really hard. Yes, I guess everyone should have training to realise that they are different and they might be a bit behind but it doesn't mean that they're stupid. It just means that they're taking a bit longer to learn it than other children of the same age. We're quite grateful that he's a summer born because at least schools generally are accepting that summer borns are usually further behind than... If he'd been born in September, the expectation for him would be, well, you're the oldest in the year...

Definitely, I mean, we went back to some of the hospital meetings, like a Tuesday group where you could drop in and talk to the other mums that were in the hospital but I had some of my friends who won't even go back to the hospital because it just associated with times of no control and feeling completely helpless. I think, yes, long-term effects can be...and I'm currently pregnant with my second and I am feeling already anxious and thinking, will I make it to term? Do we have to go through all that again?

The important role that is played by Children's Centres in providing support to parents was mentioned by four parents.

2.4.3 Transitions

Parents discussed the need for transitions to be carefully managed including home visits and recording information about birth details so that they can adapt the environment.

2.5 Compulsory education

For the parents whose child was already attending compulsory education, three said the teachers were aware of premature birth, whilst the other two were not. Three teachers had adapted their teaching methods whilst the other had not.

One the whole parents felt that schools did not understand the physical, socio-emotional or health impact of premature birth. Parents said that it would be useful to mention to staff about prematurity when enrolling children at school so that staff are aware the child might need extra time for activities and tasks.

One parent (parent 2) expressed her concern about her son starting school soon as he is pre-verbal:

If he's upset or got a problem or something's happened he can't verbalise it. He's still in nappies and I'm really worried about him.

The same parent stated that she would be delaying her son's entry to formal education with the support of her Local Authority who had been very supportive. In terms of starting school, she was concerned about her son's physical and socio-emotional development and wondering where she would find a school uniform to fit him since she had found difficulties finding clothes for him to start nursery. One parent said they would be delaying school entry for similar reasons. Another two parents said they would have delayed school entry if this had been offered to them. One parent said she had considered delaying school entry but decided against it as she was concerned that her child might experience social difficulties if placed in a year group where her peers were of a different chronological age. One father said that

Yeah, potentially we could look to delay her till actually she's just gone five I think. So she's got a preschool place for 15 hours, so we've just got confirmation of that today as to where she's going, we had to apply for that by March whenever it was this year, it was actually literally today the email has come through that the school wanted to take her. And we went round a few schools and the reason that school got chosen was because the three schools we went to, two of them have flat out said they would not be interested in even considering allowing her to delay regardless of any potential outcomes. And so regardless of all the studies that show that delay in premature babies who are born so close to the cut-off is often a good thing, regardless of any of the feedback from the observations, etc. What they all said was, we'll put her straight into reception, see how she goes, if she doesn't do alright then she can always go back a year. I said, we don't really want her to do that, we want her to start in the right year and stay, make a decision, but if it's one way or the other, and I'm not saying that she has to go back or not, we want to look at all the evidence at the end of when she's due to go into reception and if she isn't, give her another year in preschool and then move her into reception so that she stays with the same friends then all the way through. But I got told, well, how do you know she's not going to do alright, I said, well, there is quite

a lot of evidence, at least I can discuss it, two of the head teachers were not remotely interested in discussing it with me which I was really quite surprised at actually. One of them agreed that we would sit down at the end of this preschool year that she's doing, because actually their preschool and nursery classes are in the same class, and so she does one year of preschool, it will be with a large group of children, so she said all that would happen was that some of the children she was with would go up into reception but she would stay in there with the children who came up from nursery, so she wouldn't lose quite as much because she'd still be with some of the same children, and then we fought with them. So we've agreed halfway through this year we'll start to review what she should do, which is one of my main criteria for the school but there are quite a few other things, the nursery she goes to at the moment keeps sending her home with things with spelling mistakes all through does worry me quite a lot. So that was a big driving criteria for us, but it was quite a shock to me that schools say that, because that's not what it says in the government guidance at all

Three parents had or were delaying school entry for their child.

3. Discussion and conclusion

Parents were interested in telling their story as evidenced by the high number of responses to the survey.

From the survey, in terms of hospital experiences, over half of all parents were given sufficient information on practical aspects of caring for a prematurely born infant such as feeding. However, nearly half of all parents were provided with insufficient information about the long-term implications of premature birth in relation to their child's development. From interviews only three parents had received enough information about their child's long term development. For all three parents, their child had been at risk of death. Parents from the survey and interviews would also have liked more information about support for themselves and their baby on discharge from hospital. From interviews two parents would have liked to have known about the risk and potential implications of premature birth during their pregnancy.

High numbers of parents responding to the survey are not able to hold or touch their baby immediately following birth and for many parents this had not happened until a week has passed. This was a source of distress for parents and some parents talked about the detrimental effect this had on their relationship with their infant.

Nearly a third of parents from the survey described their hospital experience as positive overall whilst a similar number described their hospital experience in negative terms.

In terms of coming home from hospital, ten parents from interviews described their experiences of 'a different kind of normal'. This related largely to their emotional experiences of parenting. Five of them talked about PTSD. Only eight parents had support from family members.

Half of all survey parents had attended parent and toddler groups and the various types they attended are shown in table 3. However, many parents did not attend these groups due to health concerns (for them or their child), perceived lack of understanding from other parents about premature birth, the unsuitability of the groups for children born prematurely and/or multiple births or lack of access to such groups in the area. Non-attendance at these groups sometimes had the effect of isolating parents. A small number of parents had found specialist groups near to them which they found useful. Nine parents from interviews had attended parent and toddler groups and the others hadn't for similar reasons to the survey parents.

In terms of early help and support from professionals, few parents responding to the survey had been provided with support. Some parents talked about the difficulty they had experienced in obtaining support from professionals for their child on discharge and in particular they mentioned that their health visitor had insufficient information about premature birth. The majority of parents (9) from interviews shared negative experiences of health visitors whilst the remaining four shared positive experiences.

From the survey one third of the children reported on were attending pre-school education and the majority of parents were able to send their child to the pre-school of their choice. Most parents informed pre-school staff that their child was born prematurely but only half of parents who had informed staff said that the pre-school had subsequently asked about any developmental delays/difficulties resulting from this. Nearly half of the parents said that the pre-school had adapted their strategies to support their child, whilst the other half had not. A small percentage of parents said the setting had not adapted their strategies even though this would have benefitted their child. From interviews parents stressed the importance of communication with pre-school staff and the importance of early years staff understanding the impact of premature birth on children's development.

All parents would like pre-school staff to receive training about premature birth as can be seen in figure 5 and some parents would also like them to receive training about multiple births.

A small number of survey parents were given information about delaying school entry whilst nearly one third would have like more information about this.

In terms of starting school, from the survey the majority of parents informed school staff that their child was born prematurely, but only a third of school staff adapted the environment or teaching strategies to support their child whilst nearly two thirds felt that their child needed extra help at school. From interviews parents reported mixed experiences of teachers understanding of premature birth and their ability and willingness to adapt the environment and teaching strategies.

Overall this research contributes to other research in demonstrating the areas in which parents of children born prematurely would like more support. One pressing area in terms of parent – child relationships is the concern that parents are left emotionally distressed and this appears to need closer monitoring from the point of discharge from hospital to ensure positive relationships and mental well-being for children and parents.