

A different kind of normal:

Narratives from parents
about early care and
education for young children
born prematurely

**Interdisciplinary perspectives on premature
birth:**

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City University**

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Completed weeks of gestation

22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41
															Term				
All Preterm																			
Very Preterm										Moderate	Late								
Extremely																			
22 to 27 weeks Babies born extremely preterm are at high risk for intellectual impairment and physical disability later in life. Although the vast majority attend mainstream school, just over half require some degree of special educational support.					22 to 31 weeks Children born very preterm are at high risk for cognitive deficits and attention, behaviour and emotional problems at school age.					32 to 36 weeks Most preterm babies are born late and moderately preterm. Even these babies born a few weeks early are at slightly higher risk of developmental problems than babies born at term.					Preterm birth In the UK, around 7% of babies are born preterm each year. This means that two children in an average sized primary school class are likely to have been born preterm.				

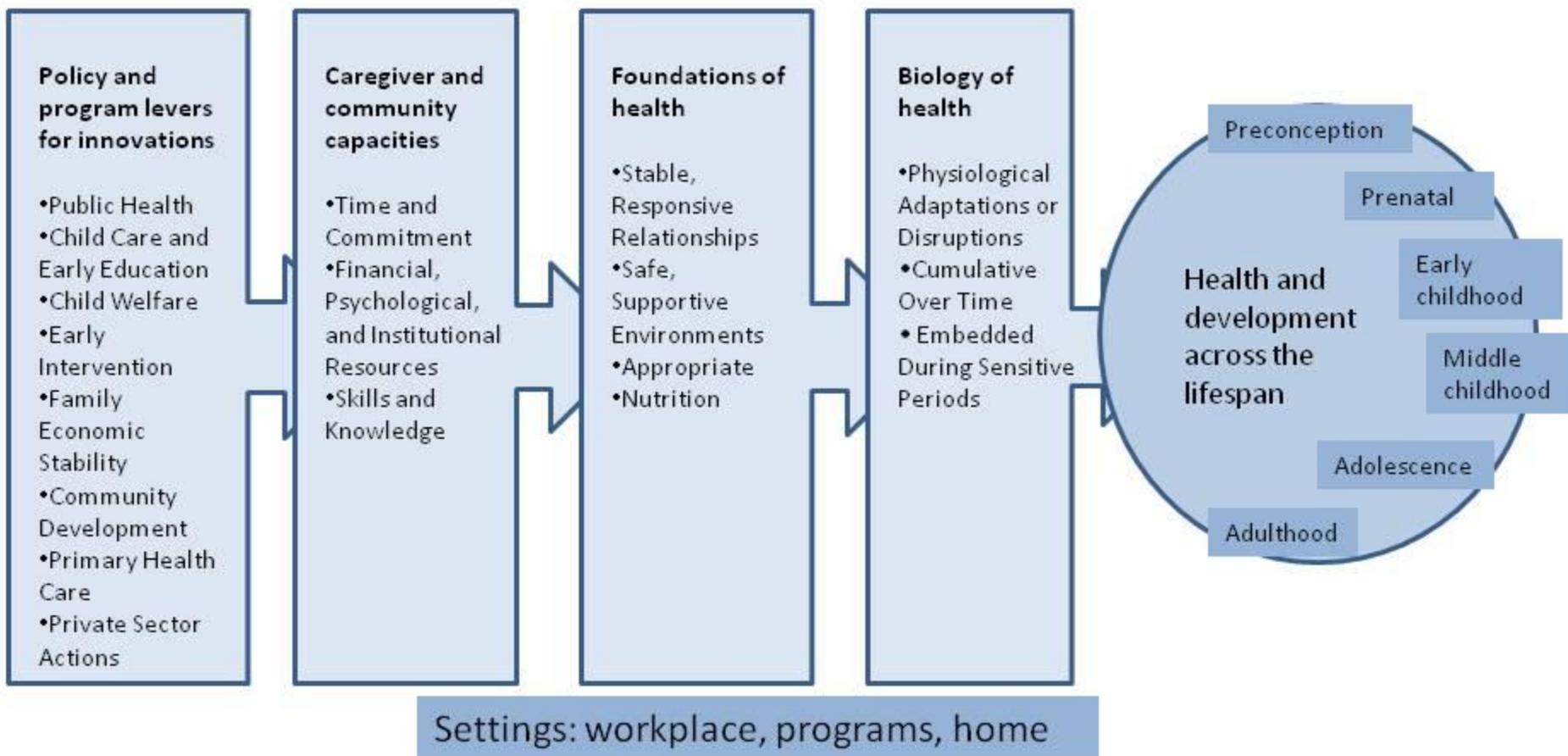
Each year in England, around 10,000 children are born very preterm (at less than 32 weeks gestation) and a further 60,000 are born moderately preterm (at 32-36 weeks gestation).

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 Programme, 2015).

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.

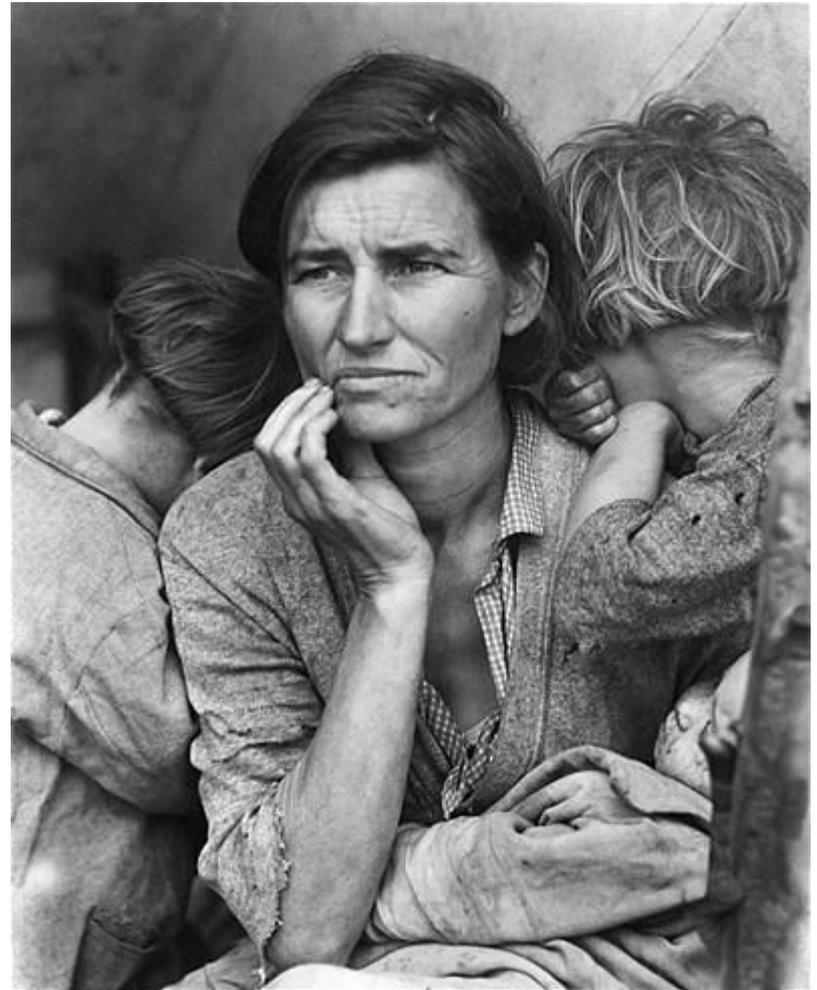
Teachers and educational psychologists receive little formal training about preterm birth and are often not aware of appropriate strategies to support preterm children in the classroom.

Bio-psycho-social model of early childhood development



Premature birth and maternal well-being

- 50% of mothers of children born pre-term experience post-traumatic stress disorder which if untreated can persist for years after birth (compared to 3% of mothers of term children)
- Factors which affect the risk for this are familial risk factors for anxiety and depression and social support provided by family and professionals
- This places emphasis on the skills and knowledge of the early childhood and education workforce to support families

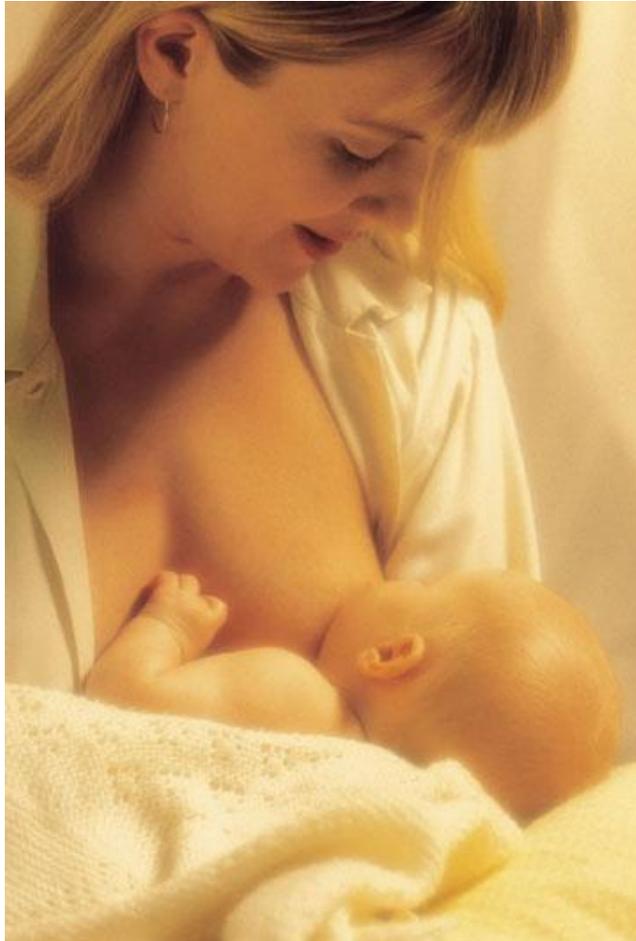


This study aimed to explore the early care and education experiences of children born prematurely through reports from parents. Research questions included:

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



“A DIFFERENT KIND OF NORMAL”

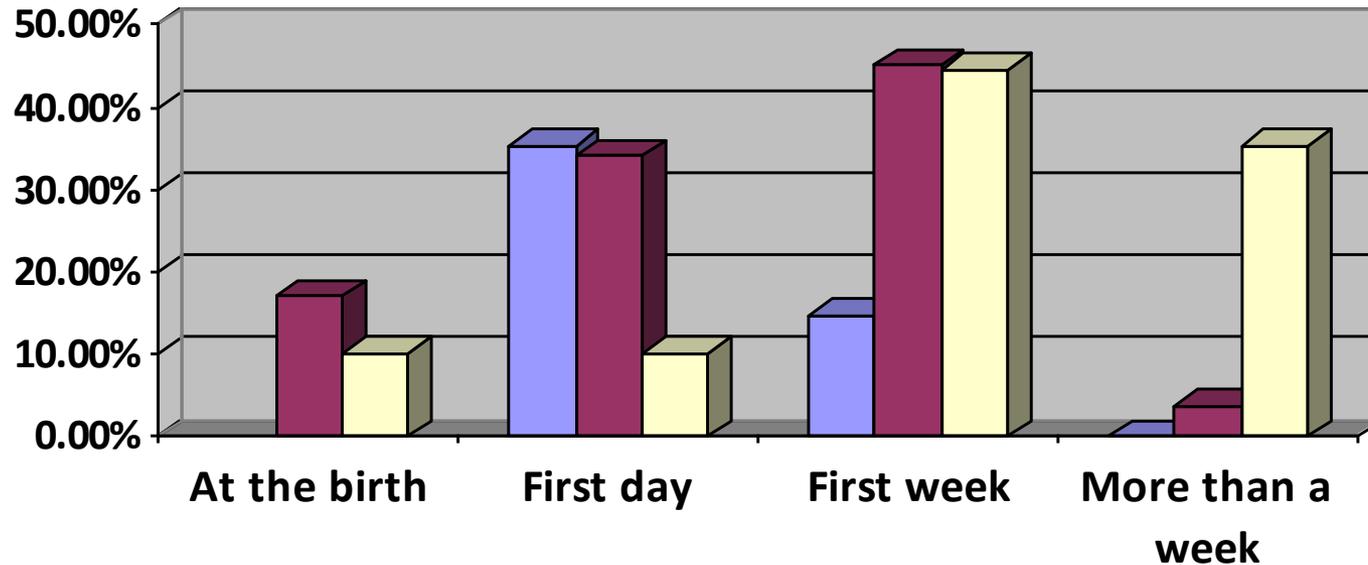


Half of all parents reported their hospital stay as a negative, frightening, isolating and traumatic experience. The other half either related positive experiences or said that the support from staff made a bad experience manageable.

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

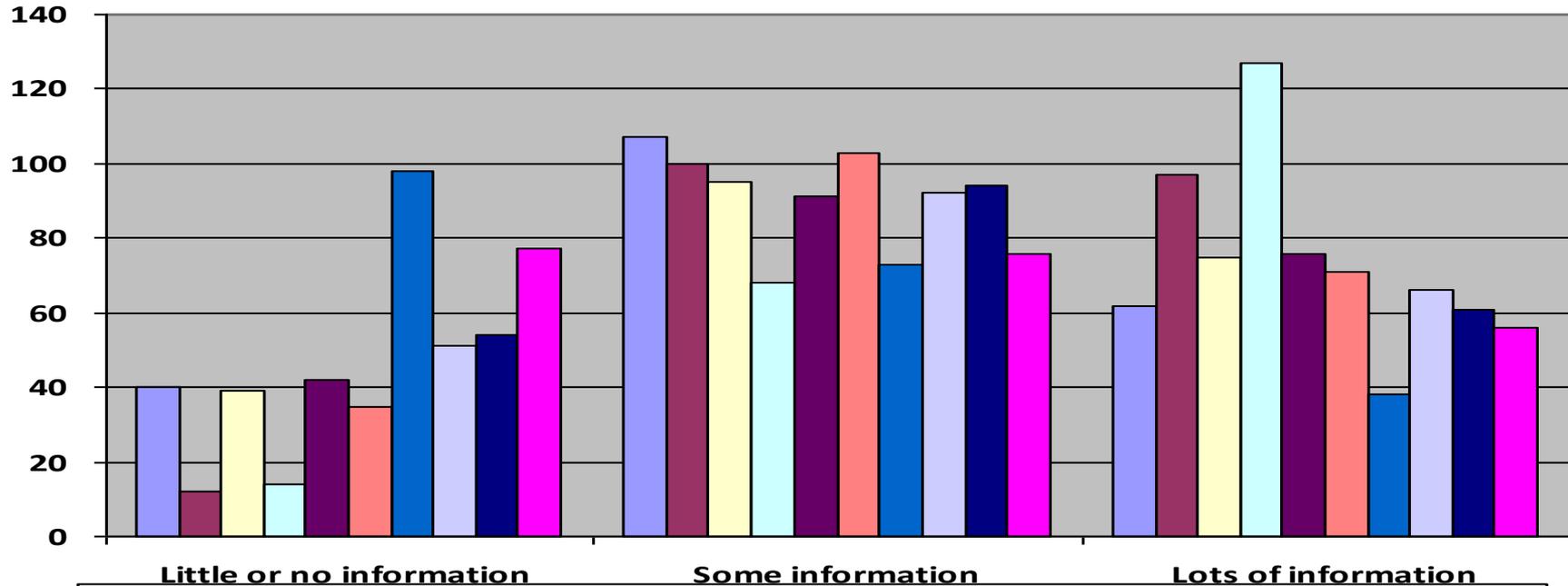
I still get upset about my time in hospital I felt like everything was medicalised to the point where any baby bonding time I had to ask for. Most of the time, I felt like I was visiting someone else's baby. I had to ask permission to feed, change or get my baby out for a cuddle. I know this was for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

First experiences between parent and child



■ First time saw baby ■ First time touched baby ■ First time held baby

How much information parents were provided



Little or no information Some information Lots of information

- Prematurity
- Your role in your baby's care
- The equipment used to investigate your baby's problems
- Feeding your baby
- Your baby's nutritional needs
- Your baby's growth and development
- Long term outcomes for your baby
- Plans for follow-up after discharge home
- The general care you would give your baby at home
- Support available after discharge



“I was very concerned about the impact it [premature birth] 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.”

I needed more information on 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.

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.

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

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 didn't 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.

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).

There also seems to be a paucity of information about support after discharge given that nearly 80 parents report little or no information, the same number reported some information and only 58 report lots of information on this aspect. Fifty nine parents had residual questions on leaving the neonatal unit. 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:

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

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 she 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.

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.

Early childhood intervention – fragmented services

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.

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.



Support in the community – the important role of Health Visitors

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.

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 health visitor made me very stressed about my daughter's poor weight gain. 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 says the same thing

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...

Twins born in 2010 at 28 weeks (very preterm)

“Severe and several allergies, asthma, hypermobility, 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 “.

A Different kind of normal - coping

One of the first things they said to me was premature babies are automatically assigned a social worker, which to me, I already **felt like I'd failed James 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.... **then...the guilt and the fear fed each other**, 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, he's going to die.**

A Different kind of normal – (not)coping

I literally lost the plot, and it sounds ridiculous now, but **I was banging my head on the wall, and ripping my clothes off.** I went to the GP and I said, I'm going to either kill one or the other of us, I cannot cope any more, someone is going to have to help me. And this is a year post natal.

And they said, **well you don't really class as post natal anymore, you don't fall under maternity services, we'll refer you for some counselling, but it might be four months.** I thought, right, well I'm sitting here at absolute crisis point, **and I can't cope any more.** And the GP just said, well there's not really anything I can do. And that's when I rang BLISS who started some counselling straight away, and we went for a course of 12 weeks of couples counselling, and that **saved my life, I'm sure, 'cause it was dire.** Nobody ever mentioned that you've got, and maybe they thought I knew, but you're not a staff member are you, when it's your baby that's in there?

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A Different kind of normal – (not) fitting in

At parent and toddler groups 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.

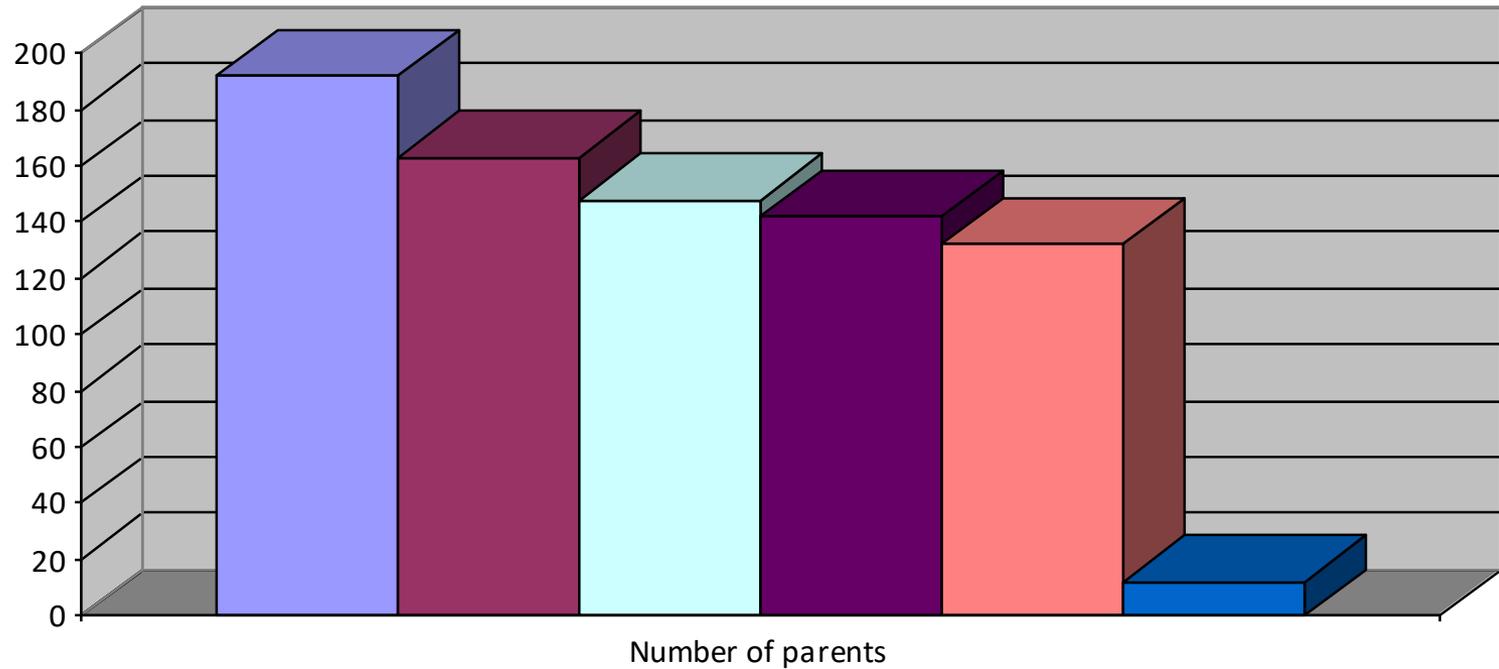
It was **three months before I found out I was pregnant and then I had him at six months**, I didn't have a particularly big bump, I hadn't really felt him moving. I certainly hadn't got to that heavy, waddling, can't wait for baby to come, didn't do any of the nesting, any of the planning. So I kind 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.

A Different kind of normal – the role of peer support

To a certain extent no things were normal because his development was that little bit different to other people who would have children. So, yeah, probably would have been good to know in our last couple of weeks in the NICU to know that there was something out there, even if it was just something someone to talk to.. other parents who had shared the same experiences and knew what I meant



What information do early years professionals need to support children born prematurely and their families?



- Training about learning and development impact of being born prematurely
- Training about the medical and health impact of being born prematurely
- Training about the psychological impact for parents of having a child born prematurely
- Training to support children born prematurely with transitions into pre-school / school
- Training to support children born prematurely with attachments and relationships
- Other

What do parents want early years professionals to know (other category)?

- Child development/developmentally appropriate practice
- How to use specialist equipment (tubes etc)
- 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 i.e. certain issues around behaviour and helpful ways to support the twin/multiple dynamic
- Appropriate physical activities for children born prematurely
- Understanding of the concept of 'corrected age'

Early year's professionals understanding and awareness of premature birth (they need to know:

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!!!!

[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

In terms of early years professional's understanding and awareness of premature birth,

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 mental health 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.



Teachers understanding and awareness of premature birth – what did they ask about?

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 / schools understanding and awareness of premature birth,

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.



Teachers / schools understanding and awareness of premature birth,

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

My son had an EHCP to ensure the most suitable school. The school where very understanding & supportive but I believe this is down to have 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 she 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

Implications for early years practice / early years workforce (and schools)

- Ask about premature birth as part of the normal registration process and questions about pregnancy and early experiences
- Understand that they may have had a traumatic journey (possible 'near death' experience) with their child / possible death of a twin / multiple
- Remember that the child may have received multiple interventions, some life saving and that trauma for child/parent may have been prolonged over several months / years
- Understand that the trauma may have caused family / marital breakdown – remember that Fathers can be traumatised as well as mothers
- Remember the effect of this on siblings, grandparents and wider family members
- Remember that children born prematurely might not have attended parent and toddler groups / other social groups so may need extra time to settle - think about the settling in procedures / policies – do they allow for anxious children and parents?
- Develop relationships with a range of Counselling services so that you can refer (one parent recommended Eye Movement Desensitization and Reprocessing (EDMR) and Attachment Parenting approaches)
- Work closely with health visitors and schools to ensure effective collaboration and to ensure that families don't have to repeat their stories multiple times
- Ensure that parents well-being has been assessed / monitored / supported
- Look at the size / height of equipment / resources to ensure that it's fully inclusive
- Pay extra attention to any signs of delays / difficulties with development and work closely with parents – in particular pay attention to any physical / movement problems that may have resulted from a difficult birth but not followed up – may result in frustration
- Work with clothing manufacturers to ensure that uniforms are accessible / inclusive
- Develop a good relationship with BLISS (and multiple birth support groups), Homestart and other agencies
- Thinking about starting / supporting a parent and toddler group for preterms / families

Implications for policy

A rigorous system of long-term assessment and monitoring is needed similar to the model available at the Champion Centre in NZ

Parents talked about the need for more discussion about the risk of premature birth during prenatal discussions / visits – to reduce the likelihood of shock

The policies for integrated working / connecting communities of practice are clearly not working for children / families of premature birth – this needs serious and immediate attention

Parents of children born prematurely should routinely and frequently be assessed for trauma – and offered mental health services as a matter of urgency

Support groups for parents of children born prematurely / multiple births need to be provided and funded

Children's centres appear to be providing important support systems for parents of children born prematurely.