# ‘A different kind of normal’: parents experiences of early care and education for young children born prematurely

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**Abstract**

The number of preterm births is increasing globally and in England, yet professional knowledge about the short and long-term developmental consequences and the psycho-social effect on parents is limited amongst the early years workforce. Using a social ecological systems theory approach this paper reports on a mixed-methods study that aimed to explore parents’ experiences of early care and education for young children born prematurely. Findings suggest that having a baby born prematurely has the potential to have a detrimental effect on parent-child bonding and can lead to post-traumatic stress disorder for parents.

Parents identified a need for professional training for early years practitioners and teachers to help them understand the concept of 'corrected age' and the extra support that children born prematurely (and their parents) might need in attending parent and toddler groups, early years settings and on transition to school especially if there are also multiple births.

**Introduction**

The number of preterm births has increased in the last two decades, and more children born preterm are surviving due to improved neonatal care (National Neonatal Audit Programme, 2015). The world health organisation defines preterm birth as babies born alive before 37 weeks of pregnancy are completed. There are sub-categories of preterm birth, based on gestational age:

- extremely preterm (less than 28 weeks)
- very preterm (28 to 32 weeks)
- moderate to late preterm (32 to 37 weeks).

Preterm birth is also sometimes defined in terms of birth weight:

- Low birthweight - Born weighing less than 2500g (5lbs)
- Very low birthweight - Born weighing less than 1500g (3lbs)
- Extremely low birthweight - Born weighing less than 1000g (2lbs)

Reaching developmental milestones may take longer for premature babies compared to babies born at full term because they are in fact younger and not always assessed according to their corrected age.

Globally, 15 million babies are born preterm each year, representing 11% of all live births. That is more than 1 in 10 babies. Approximately 1 million children die globally each year due to complications of preterm birth and many survivors face a lifetime of disability, including learning disabilities and visual and hearing problems (Liu, Oza, Hogan, Chu, Perin, Zhu J, *et al*. 2016).

In England, around 10,000 children are born very preterm and a further 60,000 are born moderately preterm. The prevalence of cognitive, behavioural and emotional problems in preterm populations has been noted. In particular, children born preterm have been found to experience specific learning problems including difficulties with mathematics, visual-spatial skills, memory and attention (Wolke *et al*, 2015).

Educators and educational psychologists receive little formal training about preterm birth and are often not aware of appropriate strategies to support preterm children in early years settings. Informing early years practitioners about the constellation of problems following preterm birth is crucial in preparing them to support the growing number of preterms entering settings in the coming years (Campbell, 2015; Carpenter *et al*., 2015).

Research 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 el 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' experiences of early care and education are an under-researched area.

**Delays and difficulties associated with premature birth**

The most common adverse outcomes following preterm birth are cognitive problems (e.g., lower IQ, poor executive function and working memory), learning difficulties, social difficulties (e.g., autism spectrum disorders, difficulties interacting and forming relationships with peers), behavioural problems (e.g., attention problems, attention deficit/hyperactivity disorders), emotional problems (e.g., anxiety disorders, phobias), and poor motor coordination (e.g., cerebral palsy and clumsiness). These kinds of difficulties can impact a child's performance and integration at school. As a consequence, preterm children are at increased risk for poor academic attainment and special educational needs (SEN) compared with their term-born peers, and poor achievement in mathematics has been reported to be especially common among very preterm children. Children's mathematics skills have been suggested to be important for their future health and wellbeing, employment prospects and income as an adult (Wolke *et al.*, 2015)

**Family systems and early care and education**

Systems theorists suggest that children grow and develop in family systems and families are embedded in broader-based social systems. Events within and between systems reverberate and have either or both direct and indirect effects on the behavior and development of children, their parents and the family as a whole. As noted by Bronfenbrenner (1979: 7):

> *Whether parents can perform effectively in their child-rearing roles within the family depends on the role demands, stresses and supports emanating from other settings…Parents' evaluations of their own capacity to function, as well as their view of their children, are related to such external factors as flexibility of job schedules, adequacy of child care arrangements, the presence of friends and neighbours who can help out in large and small emergencies, the quality of health and social services and neighbourhood safety.*

Within the context of family systems, the relationships and bonds between parents and infants are the primary influence on child development. Parents use' of responsive interactional styles that encourage children to engage with their parents is partly dependent on their psychological health and positive well-being. These aspects of parenting behavior are similarly influenced by the stressors and enablers in parents/family lives including workplace support and working patterns, policy to support parenting capacity and family/community support (Dunst, 2017). It has been found that mother's of preterm babies are more likely to show the signs of post-traumatic stress disorder (PTSD) (Drewett, Blair, Emmett, & Emond, 2004) and this may not necessarily be identified until the child is beyond infancy. Having a premature baby may result in parents experiencing a sense of loss of personal control over events, particularly those related to the survival of the infant (Meck, Fowler, Caflin, & Rasmussen, 1995). Parents may also experience a loss of their role as decision makers and care givers of their child (Campbell & Fleischman, 2001) that could result from parent-infant separation brought about by hospitalisation (Moehn & Rossetti, 1996). Parents' ability to provide responsive caregiving may be compromised in such situations.

Taking this into account, the role of early years practitioners in providing support for families is significant.

**Aim of research**

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

1. What are the early social experiences of young children born prematurely (as reported by parents)?

2. Where children are attending early years settings, what are parents experiences of this, were there any difficulties/problems in finding suitable childcare provision?

3. What do parents want early years practitioners to know about premature birth?

**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 although not all parents answered all of the questions. 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.

**Ethical considerations**

Ethical considerations related the power relationships between researchers and participants and the sensitive nature of research questions. All interviews were conducted at a time convenient for the participant. The guidelines from the British Education Research Association were followed at all times. The researcher monitored participants' speech and vocal expressions at all times for signs of distress and discomfort. Participants were informed of their right to informed consent, right to withdraw from the research at any time and to confidentiality and anonymity.

**Data analysis**

Data were analysed to answer the research questions at the first level allowing common and discrepant themes to emerge subsequently. Research questions identified *a priori* themes and thereafter emerging themes were identified. Qualitative content analysis provided the opportunity to organise, condense and categorise data through a process of interpretation of and inference from participants' original expressions. This was an inductive process rather than being theory guided and deductive. A process of reducing and clustering to form initial codes or sub-categories that described followed. The unit of textual analysis was an extract from a transcription with factual connection to an idea and issue. After initial codes had been identified in data of two or three transcripts, codes were compared with each other according to similarities and differences to determine which data 'look alike' and 'feel alike' as suggested by Lincoln and Guba (1985, 347). The data analysis was informed by processes of thematic analysis – a foundational analytical method designed to identify, represent and report thematic patterns that occur within the data (Braun and Clarke 2006).

## Findings

Themes that arose from analysis of survey responses and interview transcripts related to parent's experiences of contact and bonding with their child in hospital, participation and inclusion in parent and toddler groups, transition to pre-school and transition to school including deferring entry. Two emergent themes that was threaded throughout the interview transcripts was parents' perception that they had experienced 'a different kind of normal' to parents of full-term children and parent's concerns about their child being heard (or not) by educators.

### First touch and early experiences

From the survey, one third of all parents described their hospital experience as traumatic, frightening and stressful (for a range of reasons) and the majority of parents had not been able touch or hold their baby in the first hours or the first day following birth. For many this first contact happened during the first week rather than the first hour(s) or days.

PLACE TABLE 1 ABOUT HERE

**Figure 1: First contact between parent and child**

For 35% (of 209) of parents, holding their baby only happened after a week had passed. Some parents explained that this 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. I was 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.*

> *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..*

In terms of leaving hospital both survey and interview parents discussed the lack of comprehensive discharge plan and insufficient community support. Five survey parents and five interview parents mentioned that they had been diagnosed with post-traumatic stress disorder (PTSD) that was not diagnosed until their child was beyond infancy:

*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 was a year post natal.*

**Attending parent and toddler groups**

From the survey parents said they had attended a wide variety of parent and toddler groups with their children, from general parent and toddler groups to groups that focused on music or gym activities. However, a proportion of parents did not attend parent and toddler groups due to non-availability of suitable groups, time and / or cost constraints as explained below and elaborated on in Table 1:

*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.*

*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.*

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

For a proportion of parents, non-attendance 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.*

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 also reported that they did not attend 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 was not the case, they felt internal pressure for their child to be at the same stage as other children or they felt that they could not 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 practical 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.*

PLACE TABLE 1 ABOUT HERE

From interviews 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 with twins/multiples for the other. For parents who had not 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 attend due to the high cost of such groups. Others said they didn't attend such groups because their child was not developmentally ready (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 the she refrained from attending groups because she did not feel that other

parents understood her experiences of post-traumatic stress disorder. Another said she had not 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 premature birth mum attended so there was a shared experience. 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 Rhyme time sessions at the library. 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. 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. What we experienced was 'a different kind of normal.'*

The parent above went onto the 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 resulted from the necessary confinement in the home (for health and medical reasons.) One parent said that she paid for home-delivered services such as baby massage (normally delivered in Children's Centres) to overcome the isolation.

Another parent said that he 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.

**Pre-school education and starting school**

From the survey, 143 (68%) of children reported on by parents were 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 as shown in table 2 below.

PLACE TABLE 2 ABOUT HERE

The majority of parents (99%) were able to send their child to the pre-school of their choice (although their choice may have changed as a consequence of premature birth as discussed below). 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 the setting of parental choice being in another county which the local authority would not fund. However, 17.5% of parents changed their preference of pre-school education when their child was born prematurely. The reasons for this were varied but for the majority parents chose a smaller setting, a setting with higher adult-child ratios and/or a setting where staff had significant experience of supporting children with special educational needs.

For one mother, her child's premature birth and consequential ill health impacted on her own employment status and 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.*

**Informing pre-school staff about premature birth**

The majority (83% of 143 responses) 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. However, only 49.7% of parents said that staff subsequently asked about any developmental delays/difficulties resulting from premature birth. For those professionals that did not ask, the majority of parents 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:

*I don't think they have any appreciation of the long term difficulties in education that a prematurely born child 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 chid developmentally.

**Training for early years professionals**

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

PLACE FIGURE 2 ABOUT HERE

**Figure 2: Training for early years practitioners**

Included in the other category were:

- Child development/developmentally appropriate practice
- How to use specialist equipment (Nasogastric Intubation and Feeding)
- Understanding parents' concerns about their child's development
- 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'

One parent commented on the psycho-social aspects of having a child born prematurely that she felt early years practitioners needed to be aware of:

> *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 it 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…*

Some parents commented on basic aspects of early years provision such as equipment that would serve as a physical 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*

Another parent mentioned that the early years setting approach to children's admission and settling in procedures had caused difficulties for her son and resulted in her finding a home based early years setting that adopted a more flexible approach:

> *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!!!!*

Another parent suggested that parent-child bonds should be considered so that children's emotional well being is supported:

> *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'.*

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.*

From interviews 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 in interview 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 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 had 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.

**Child's experience of starting school/attending school**

From the survey, only 15.6% (of 43 responses) of parents reported that teachers/teaching assistants asked about premature birth on entry to primary school. 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.

PLACE TABLE 3 ABOUT HERE

Nineteen survey 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 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 sons development even further. Educators must be taught what the impact of prematurity can have*

> *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.*

One parent discussed the physical adaptations that need to be considered to avoid any peer bullying:

> *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.*

From interviews, 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 from interviews 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 whose child was due to commence compulsory education within a few months time 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.*

This raises the question about delaying school entry for children born prematurely and information provided for parents about this. Only 11.5% of survey parents were provided with information about delaying/deferring school entry for their child. Of these 9 were delaying, 12 were not and 2 were unsure:

*I would advise other parents 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.*

From interviews, one parent stated that she would be delaying her son's entry to formal education with the support of her local authority. 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 reported that despite government guidance that parents can choose to delay school entry, the response he received from schools was variable in relation to their support of this:

*We went round a few schools and two of them have flat out said they would not be interested in even considering allowing our daughter to delay regardless of any potential outcomes. 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, 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. 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. So we've agreed halfway through this year we'll start to review what she should do. It was quite a shock to me that schools say that, because that's not what it says in the government guidance at all*

**Discussion and conclusion**

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

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. As noted by Dunst (2017) the ability of parents to provide responsive interactional caregiving can be challenged when parents experience stress and psychological ill-health. 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 to help them cope with their stressful experiences.

Half of all survey parents and the majority of interview parents had attended parent and toddler groups 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. The judgement from other parents or group organisers about children's development represented a particular barrier that could be addressed with training for organisers of groups. Non-attendance at these groups sometimes had the effect of isolating parents from the communities whose primary purpose is to support them. A small number of parents had found specialist groups near to them which they found useful. However, these specialist groups are not provided for all parents in all locations and early years settings could consider providing the space and time for parents of prematurely born children to meet and share 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 the pre-school of their choice, although their choice may have changed as a consequence of their child's premature birth. For those who changed their preference this was influenced by their consideration of their child's socio-emotional and/or physical needs and resulted in them choosing a smaller setting, a setting with high adult-child ratios and/or a setting where staff had considerable experience of supporting children with special educational needs and this places emphasis on practitioners knowledge about premature birth and the potential developmental risk.

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.

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.

Most importantly, it appears that many parents do not feel that their concerns regarding their child's development and needs are given due consideration by early years practitioners and teachers. In addition they already have experienced feelings of isolation and exclusion from community groups such as parent and toddler groups and as noted by Drewett *et al.,* (2004) and parents in this study may have experienced PTSD, a sense of loss of control (Meck *et al.*, 1995) and negative hospital experience (Moehn and Rossetti, 1996). They also have experienced the loss of one child (where there were multiple births) and/or resuscitation of their child and multiple, intrusive interventions to ensure their child's survival.

The transition points between home and setting and from early years provision to school need careful planning as parents shared concerns about children's socio-emotional and physical needs. All parents would like pre-school and school staff to receive training about premature birth and some parents would also like them to receive training about the additional risk and concerns for parents of multiple births.

Overall this research contributes to existing research in terms of understanding and 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.

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