

**Research Brief: working in partnership with parents to create inclusive environments for children, aged 0-3 years, with chronic health conditions: parents' perspectives**

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**Introduction**

This research brief reports on one aspect of the findings from a doctoral research study which explored how practitioners create inclusive environments for children with chronic health conditions (CHCs). Some of the findings from the study have been previously reported (Musgrave 2013). The first stage of the Case Study surveyed 60 day care settings in a geographical area in the West Midlands (UK). There was a 31.5% return rate from the survey and 4 of the respondents went on to the second stage of the study. This briefing reports the findings from a small sample about parents and practitioners working in partnership to create an inclusive environment for children with CHCs. The study included data from a child called 'John'. John was recruited from outside the case, he has diabetes. The next section gives an overview of the rationale for the research.

**Rationale for Research**

A CHC is defined as one that is incurable and lasts for longer than three months (Brown, Krieg and Belluck 1995). In addition, the symptoms of CHCs can interfere with everyday activities. In the context of this research, the symptoms of CHCs can interfere with children accessing activities that are planned as part of their early education. Each of the conditions included in this study is characterised by a range of symptoms. For example, the classic symptoms of asthma are coughing (especially at night), wheeziness, shortness of breath and tightness of the chest (Levy, Weller and Hilton, 2007). The symptoms of CHCs can be minimised in two ways. First of all, by medication, in the example of asthma, this could be inhalers. Secondly, the child's environment can be managed to reduce the 'triggers' of asthma. Triggers are substances in the environment which may provoke the symptoms. In the case of asthma, common triggers are animals, dust, and taking part in physical activity. The most common contemporary conditions that affect children in the minority world include asthma, anaphylaxis/allergy, diabetes and epilepsy. The guidance "Managing Medicines in Schools and Early Years Settings" (2005) was a joint publication by the Department for Education and Skills and the Department of Health. The guidance includes information for staff involved with storing, administering and recording of medication for these conditions. These conditions are included in the guidance because they are conditions "that most commonly cause

concern in schools and settings” (p\_25). However, eczema is not included in the guidance, even though it is a CHC that frequently affects young children. The National Institute for Health and Clinical Excellence (2007) estimate that eczema affects 11% of children between the ages of 6-18 months. Therefore, these five conditions were selected to examine how practitioners adapt the values and principles of the Early Years Foundation Stage (2012) to make the education and care inclusive for young children with CHCs.

### **Research and Field Questions**

The over-arching research question asked how practitioners created inclusive environments for children with CHCs. However, it was important for practitioners to have an understanding of the ways in which CHCs affect children and in turn, their families in order to develop inclusive relationships with parents. The field questions included the following:-

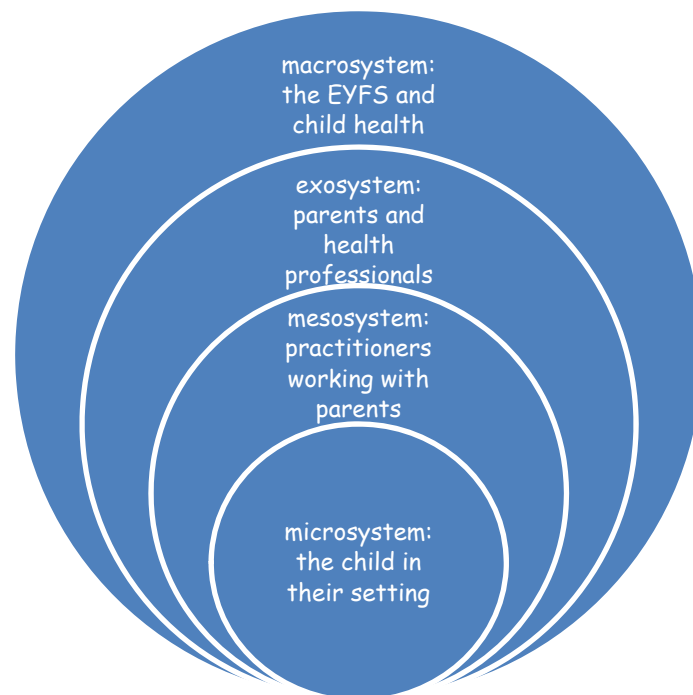
- What are the effects of having a child with CHC(s) on parents and families?
- How do practitioners work with each other, and in partnership with parents, to include children with CHCs?

The next section explores some of the literature relating to children’s health and practitioners working with parents in early years settings.

### **Literature Review**

The EYFS seeks to provide “partnership working between practitioners and with parents and/or carers” (p\_2). The discourse of practitioners working with parents is an evolving field of research. Reasons given for the importance of practitioners working with parents include the need to care, protect and advocate for children (McDowall-Clark\_ 2011). In relation to this study, using Bronfenbrenner’s (1994) model, the parents, or other carers, can be regarded as the mesosystem because they act as the “linkages and processes taking place between two or more settings containing the developing person” (p\_40). Figure 1 illustrates how Bronfenbrenner’s model can be used to explain the inter-relationship between health and education and the role of parents and practitioners working in partnership to create inclusive environments for children with CHCs in day care settings.

**Figure 1: Bronfenbrenner's ecological systems theory**



Parents are usually the best placed adults to provide information about their child and the management of their CHC. This information may originate from parents taking their child to a hospital consultation; for example, such information may include treatment changes that need to be implemented whilst the child is in their setting. In addition to medical information, parents are likely to have a wealth of knowledge that practitioners will need in order to adapt the environment and the curriculum.

Therefore, parents can be the bridge between children's exosystem and the microsystem. This requires parents to have resources to fulfil this role and this may be especially challenging for marginalised and disadvantaged parents (Field, 2010).

The information that is given to practitioners by parents will be fundamental to planning the curriculum so they can adapt activities to make them inclusive.

However, relationships with parents also need to be inclusive and developing relationships between parents and practitioners can be complex. According to Brooker (2010), developing relationships is an intricate process. It is possible that the presence of a CHC in a child adds another dimension to the development of practitioner and parent relationships. Some mothers may feel that they are being forced back to work and this may cause maternal anxieties and may create difficulties in developing relationships with practitioners. This is illustrated by Daud *et al*'s (1993) study where lower levels of maternal employment were noted in the children with eczema than in the control group. This suggests that some mothers choose to opt out of employment to care for their pre-school children. However, many mothers do not have the option of remaining at home and need to work. If mothers have anxieties about leaving their children to be cared for by somebody else, this is a consideration for practitioners to explore in order to reassure parents of their suitability to care for their child.

The literature from the health databases revealed some insights into to the experiences of parents living with children with CHCs. Gillespie, Woodgate and Chalmers (2007) reported high levels of emotional responses amongst parents caring for a child with a CHC. For example, mothers of children with potentially fatal food allergies described how they found it difficult to relax when their child is away from their supervision (Gillespie, *et al*, 2007). Parental anxieties can result in them becoming over protective and this can be conveyed to children through their parents' actions and words. In turn, further studies have shown that this can mean that a child becomes anxious and fractious (Mullins, Wolfe-Christensen, Hoff Pai, *et al*, 2007). The next section summarises the details of the parents who were participants and their contribution to this aspect of the study.

### Parents as Participants

Table 1 summarises the participants who were parents in this study. Freddie and DJ were in two different day care settings at the time of the research. John was not in a day care setting at this time and

**Table 1: Parents who participated in the study**

Research method	Relationship to setting and children in the case
June 2012: Questionnaires completed by parents (instead of being interviewed)	2 parents of children with eczema from a setting in the case
June 2012: 30 minute semi-	Mum to Freddie (33 months at the time of the

<b>Research method</b>	<b>Relationship to setting and children in the case</b>
structured interview plus emails from Freddie's mum	interview and has eczema and asthma) She came and met me at the setting during her lunch break to be interviewed.
4 x 30 minute interviews, plus emails March 2012 – March 2013	Kate (pseudonym) Mum to DJ (aged 20-32 months during the period of data collection. DJ has asthma, eczema and allergies causing dietary restrictions) DJ's mum is also a practitioner working in the setting in a different room. DJ's mum was interviewed during breaks from her work in the setting
May 2012: Family interview – 1 hour home visit plus several emails about John from his mum	Parents of John (John has diabetes and was 34 months at the time of the interview. He was not accessing early education at the time of interview).

## **Findings**

This section reports some of the findings about the effects of their children's CHC on the families' lives. The most common condition that affected the children in day care settings in this study was eczema, followed by asthma and anaphylaxis/allergy.

The lives of the parents in this study were inextricably linked with their children's lives. Therefore, the effects of their children's CHCs also impacted upon the parents.

This section reports some of the effects as reported by the parents in this study. The findings from this study revealed some of the ways that the symptoms of their children's CHCs impacted upon parents. The findings were grouped under the following headings:

1. Family routines and activities
2. Parental concerns caused by their child's CHC(s)
3. Parents as experts in their children's health
4. The importance of communication between parents and practitioners

The following sections will report and discuss the findings and highlight the implications for practice.

### **Family routines and activities**

The parents reported how they had to plan ahead to avoid situations that may provoke the symptoms of their children's CHC. One mum reported the number of considerations that her son's asthma and eczema presented and how this meant there was a lack of spontaneity because of the need to plan ahead. She commented:

All this sounds really bad, I love him and would never change him, but this is our life and we try to make it as nice as possible for him. We don't miss out on things, we just have to be a bit more careful planning them

The need to plan ahead in order to avoid triggers for their children's symptoms was echoed by all of the parents who participated in the study. The data from parents highlights considerations for practitioners who will have to consider the extra planning required for certain activities, such as trips away from the setting.

The effect of the symptoms of CHCs (especially scratching caused by eczema) affected the sleep routine of the child with CHC and in turn, this affected the parents' sleep routine. DJ's mum reported how lack of sleep leaves her exhausted:

When I sit down in the evening, that's when the exhaustion kicks in. We do shifts, I go to bed early ... he'll (her partner) stay up later because he knows that DJ will get up at some point, usually at midnight, but sometimes he can go through until half past five, but he is awake every 2-3 hours.

The impact of sleep deprivation on parents can be a stressor (Swick and Williams, 2006) that is likely to have significant impact on the well-being of parents. The implication for practitioners is that there is a need to be aware of such additional stressors and develop ways of working to support parents.

### **Parental concerns caused by their child's CHC(s)**

The findings in this section illuminate some of the difficulties that the parents interviewed in this study faced on a day-to-day basis because of their children's CHC. Mullins, *et al* (2007) reported that parents of children with asthma and diabetes exhibited signs of psychological distress as a consequence of the uncertainty that can surround the health of their children. They go on to suggest that parental response can be seen as being over-protective of their children. Again, this highlights the importance of practitioners being aware of the emotions that parents may be experiencing. Such awareness may help practitioners to develop positive and inclusive relationships with parents. The data from the parents suggest that it is possible that all parents in this study experienced, and were still experiencing, a range of emotions because of their child's CHC. Freddie's mum talked about the time when Freddie was a baby and he cried because of the pain of the eczema, which at that time had not been diagnosed:

I can remember him as a baby, crying and upset because his skin was so inflamed all the time. Even though he is a happy toddler now, when he was a

baby he was always crying because of how his skin was, but we didn't know that at the time and we were treating him for all these other things we thought he had.

Although Freddie's mum was not explicit about her emotions at this time, her words suggest that she may have felt a sense of bewilderment about why he was so tearful. This finding is an important consideration for practitioners because it illustrates a scenario where the behaviour of a baby like Freddie in a day care setting could be misinterpreted. Freddie could have been labelled as a "fussy baby" (Gonzalez-Mena, 2007, p20). A baby who is "fussy" may impact on how the relationship develops with his Key Person.

John's mum reported how she worried about managing the insulin injections for his diabetes:

The first injection I did, I remember I just sobbed and thought I'm not going to be able to do this. He couldn't understand why mummy was hurting him

Her comments convey the anxiety and distress that she experienced at this time. This would have been a difficult time for John and his parents and it is clear that they were experiencing stress because of John's CHC. The manager at John's setting appeared to be unable to recognise their stress and failed support the family. John's mum said, "the manager said she couldn't understand what all the hassle was about, and it was easy to see when diabetic children were poorly". Following an incident when John became unwell and the manager failed to respond appropriately, John's mum's anxieties about leaving him at the setting intensified and eventually she withdrew him from the setting. At the time of the interview, John was not in early education.

### **Parents as experts in their children's health**

The data suggested that the ability of practitioners to meet children's health needs was reliant on the parents' knowledge about their child's condition. Parents were seen, and acted, as a conduit for information (including information from health professionals) to practitioners that they had accrued about the management of their child's CHC. In turn, this knowledge was passed on to practitioners in order to inform them of how to plan for their needs and to adapt the curriculum accordingly. Consequently, some practitioners developed some of the features of being expert in these children's health. The transfer of this knowledge from parents to practitioners helped them to plan the unique health needs of children. This is supported by John's

mum's belief that diabetes affected him in a way that is unique to him. She said, "I know little things that they don't know about John and just because he has got diabetes, it might be slightly different to another child's diabetes." John's mum's comment highlights the importance of the parental role in their depth of knowledge about their child's health care needs. The findings revealed that it was essential that parents and practitioners had a shared understanding of the needs. The data suggested that key to developing a shared understanding was the need to communicate effectively.

### **The importance of communication between parents and practitioners**

The data highlighted the need for effective communication between parents and practitioners. The modes of communication were written and verbal. They were also planned and unplanned. An example of an unplanned communication was illustrated by the comments of a manager who described the effect of a phone call to a parent in order to clarify a point:

the parents were always at the end of the phone for us just to check. They were really appreciative that we actually rang, we would say, we know it's probably silly, but can we just ask? They said that they would prefer that we actually ring than not at all

The data from the parents suggested that the parents were reassured by such phone calls. The parents felt that communications throughout the day helped them to feel confident that their child was being cared for and their health needs were being met.

### **Discussion**

The findings of this study suggest that the symptoms of CHCs have a range of effects on children and families. Brooker (2010) reminds us that it is important that practitioners are aware of the factors that add to the complexities of the lives of all children and their families. The data in this study highlights the complexity that the symptoms that CHCs can cause and how they can affect children and families. Abbott and Langston (2006) highlight the pressures on parents caused by working and caring for their children, again the data suggests that caring for children with CHCs can be another pressure, which may be underestimated. Swick and Williams (2006) report the stressors that can impact on families, such as violence and chemical dependence. However, the emotional effects of being a parent of a child with a CHC may be an additional stressor for parents. However, the ability of practitioners to empathise with parents and appreciate some of the pressures that



they may be under may help to strengthen the relationships between them. This can lead to a greater awareness of the needs of the family and in turn this can promote inclusion of the whole family, as well as children with CHCs.

An important finding that has emerged from this study was how the parents became expert in managing their children's health. This expertise was a valuable resource for practitioners to help them plan inclusively. The parents were able to be the "linkages and processes taking place between two or more settings containing the developing person" (Bronfenbrenner, 1994, p\_40). Their ability to fulfil this role meant that they were able to work in partnership with practitioners in order to create inclusive environments for children with CHCs. However, if parents are unable to fulfil this role, it may be that their children are not included in their early education. The findings reinforce the importance of the role importance of practitioners and parents working in partnership. In the context of this study it would appear that positive relationships are essential to create inclusive environments for children with CHCs.

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