

How do practitioners create inclusive environments in day care settings for children under the age of five years with chronic health conditions? An exploratory case study

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Dedication

This thesis is dedicated with love and joy to my daughter

Nicky

who died in 2006, aged 18



When you are joyous, look deep into your heart and you shall find it is only that which has given you sorrow that is giving you joy. When you are sorrowful, look again in your heart, and you shall see that in truth you are weeping for that which has been your delight (Gibran, 1923)

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Abstract

The concept of inclusion within the English education system is often taken for granted. There are a number of factors that can impact on inclusive practice and this demands careful exploration. Chronic health conditions (CHCs), such as anaphylaxis, asthma, diabetes, epilepsy and eczema, pose particular challenges to inclusion for practitioners who teach, educate and care for children under the age of five years in day care settings. These conditions can have a significant effect on children's health, especially in the minority world. However, there is a paucity of research about how the symptoms affect children's early education.

This mixed-methods study collected quantitative data by sending a postal survey to 60 settings in order to find out how many children are affected by these conditions in day care settings. Four of the surveyed settings went on to participate in the qualitative aspect of the study. Qualitative data were also collected from parents of children with CHCs and the study included observations of a child in his early childhood setting over the course of a year.

The findings revealed that 11% of children attending the settings in this study had been diagnosed with one or more CHCs and that CHCs had a profound effect on children and their parents. Parents reported that knowledge of the specific conditions is important for practitioners to have in order to create inclusive relationships with them. Practitioners in this study demonstrated a collaborative approach to leadership when creating inclusive environments. However, the findings revealed

tensions for practitioners regarding the inclusion of all children in the curriculum. The findings suggest that achieving inclusion may therefore be problematic for some children. However, the communication skills, knowledge of CHCs and willingness of practitioners were vital to the inclusion of children with CHCs in their early education.

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Chapter 1: Introduction

Overview

The Early Years Foundation Stage (DfE, 2012) (EYFS) is the Statutory Curriculum Framework in England for providers of Early Childhood Education and Care (ECEC) from birth to five years of age. An overarching principle of the EYFS is "to provide equality of opportunity and anti-discriminatory practice, ensuring that every child is included and supported" (p.2). Definitions of what is meant by inclusion are discussed in Chapter 2. However, the aim of this study resonates with Nutbrown and Clough's (2006) definition that "inclusion may be seen as the drive towards maximal participation in and minimal exclusion from early years settings, from school and from society" (p.3). This study explored how practitioners in early years settings implemented and adapted the EYFS in order to minimise exclusion and maximise participation for children aged five and below with chronic health conditions. Therefore, this definition is consistent with the intention of this study, which is to contribute towards a theory of inclusive practice for children with chronic health conditions.

A chronic condition is one that is of long duration (Oxford Concise Medical Dictionary). Furthermore, chronic conditions are incurable and the symptoms of these conditions can interfere with daily life (Brown, Krieg and Belluck, 1995). The impact of chronic conditions on children's activities is an on-going consideration because they may be restricted from joining in some activities for considerable periods of time. This is especially the case for young children accessing

their early education. The ways that chronic conditions can impact on children's inclusion in their early education is the focus of this study. There is a need to examine the significance of these chronic health conditions on children, because the effects on children can be under-estimated or possibly over-looked. The effect of symptoms of these conditions may be minimised if there is an understanding of the signs, symptoms, treatment and triggers that characterise each condition. Such understanding is vital for practitioners to bear in mind when considering ways to make the curriculum inclusive for children with chronic health conditions. However, it is also important to be aware that, even if there is careful management of the effects and symptoms, there can still be a significant impact upon children's health, meaning they may experience suboptimal health. As a consequence, children may experience poor wellbeing, which can impact on their learning. Figure 1.1 summarises the inter relationship between health, inclusion, wellbeing and learning.

Figure 1.1: Inter-relationship of chronic health conditions on health, inclusion, wellbeing and learning

minimise the impact of symptoms of chronic conditions on children by

- adapting the environment
- helping children to cope with the environment

optimise children's feelings of 'being healthy'

increase feelings of well-being

increase participation in early childhood education - being included

increase developmental outcomes

increase individual educational attainment

increase personal contribution = increased sense of well being

The considerations that need to be borne in mind in order to make the curriculum inclusive for children with chronic health conditions are an additional layer of complexity. This is an important point for early years practitioners because this can mean that children in day care settings may be excluded from some aspects of early childhood education. The effects of exclusion may have an impact on children's wellbeing. This is a term that can have a range of definitions, however, definitions of wellbeing frequently link health as a factor that can influence an individual's sense of wellbeing. The Oxford English Dictionary defines wellbeing as "the state of being comfortable, healthy or happy". Statham and Chase (2010) define wellbeing as "generally understood as the quality of peoples' lives... it is understood both in relation to objective measures, such as... health status" (p.2). Laevers and Heylen (2003) measure children's level of wellbeing by assessing their involvement in activities. Therefore, it can be argued that children's wellbeing can be improved by minimising the effect of chronic health conditions on them, as well as by adapting activities to make them inclusive, thus maximising participation in early years education.

The chronic health conditions that are included in this study are very different conditions from each other and have different signs and symptoms. However, anaphylaxis, asthma and eczema are regarded as allergic (or atopic) conditions and it is not unusual for children to have a combination of two, or all of these conditions. Furthermore, anaphylaxis and allergy are descriptions of conditions that are often used interchangeably. Health conditions are diagnosed by the presence of signs and symptoms.

The Oxford Concise Medical Dictionary (2010) offers the following definitions:

- Sign: an indication of a particular disorder that is detected by a physician while examining a patient but is not apparent to the patient
- Symptom: an indication of a disease or disorder noticed by the patient
- Trigger: a substance that can exacerbate symptoms of chronic health conditions: for example, dust can exacerbate the symptoms of asthma.

Please note: For the remainder of this thesis, unless otherwise indicated, the use of the words child, children, parent, and parents refer to a child (children) under the age of five with chronic health condition(s) or their parent(s). Similarly, the use of the term practitioner(s) refers to those professionals caring for such children. In addition, to avoid repetition, the term 'chronic health conditions' will be abbreviated to CHCs.

Table 1.2 summarises important information about the conditions in this study. It includes information highlighting substances that can 'trigger' the symptoms of CHCs, as well as a summary of the possible impact on inclusion.

Table 1.2: A summary of the chronic health conditions explored in the study

Chronic condition and incidence	Description of condition	Signs and symptoms relevant to practitioners	Typical triggers in a setting	Possible impact on inclusion	Treatment
<p>Anaphylaxis</p> <p>6% of children diagnosed (NICE, 2011)</p>	<p>Severe allergic response (potentially fatal in rare cases). High incidence of children having other allergic conditions such as asthma and eczema</p>	<p>Rash, breathing difficulties, swelling of airway, lips and eyes, runny nose, vomiting</p>	<p>Foods (commonly nuts, kiwi, egg and lactose), animal dander and hair, latex</p>	<p>Managing the environment in order to remove the risk of contact with a known allergens may impact on some activities, e.g. contact with certain foods and animals</p>	<p>Avoidance of the allergen. Anti-histamine or adrenaline auto-injector (Epipen) if allergy triggered</p>
<p>Asthma</p> <p>10-15% of children affected (NICE, 2013)</p>	<p>Inflammation of the breathing airways. Can be associated with allergy. Often exercise induced. Attacks can be fatal</p>	<p>Wheeze, cough and difficulty in breathing</p>	<p>Contact with allergens can trigger an asthma attack. Common triggers include dust, animal hair and saliva, pollen, chemicals, aerosols, physical activity, moving between contrasting temperatures and</p>	<p>Avoiding contact with an allergen can result in a child not taking part in certain activities. Reduced physical exercise. Reduced outdoor play in cold weather and during pollen</p>	<p>Reliever inhalers (blue) are frequently prescribed to be administered via a spacer device to give extra relief if a child is in contact with a trigger for their asthma. Preventer inhalers (typically brown, orange or purple)</p>

Chronic condition and incidence	Description of condition	Signs and symptoms relevant to practitioners	Typical triggers in a setting	Possible impact on inclusion	Treatment
			viruses. Emotions such as crying, excitement and laughter can trigger a response	season	are usually prescribed for twice a day use and can be given at home
<p>Diabetes Mellitus</p> <p>Affects 4% of children aged 0-4 years (Diabetes UK, 2012: NICE, 2004)</p>	<p>Usually an inherited condition where the pancreas produces no or insufficient insulin (the hormone required to metabolise carbohydrates)</p>	<p>Low blood sugar levels (hypoglycaemia) is a first aid emergency requiring sugar-containing food or drink, or a prescribed substance such as "hypostop"</p> <p>High blood sugar levels (hyperglycaemia) is less likely to require first aid in a setting, but does require management to return blood sugar levels to normal</p>	<p>A change in a child's expected intake of carbohydrate, physical exercise and insulin requirements can affect blood sugar levels</p>	<p>Detailed knowledge is required to adapt the needs of children with diabetes to maintain normal blood sugar levels. For example, activities that involve extra carbohydrate, such as celebrations involving food, must be planned to ensure that there is a balance between carbohydrate intake and insulin requirements. A lack of this</p>	<p>Treatment hinges on achieving blood sugar levels within the normal range. Therefore, carbohydrate intake and insulin dosage has to be adjusted accordingly. Further adjustments have to be made if the child is more or less physically active than anticipated</p>

Chronic condition and incidence	Description of condition	Signs and symptoms relevant to practitioners	Typical triggers in a setting	Possible impact on inclusion	Treatment
				knowledge may lead to children with CHCs being excluded from activities	
<p>Eczema</p> <p>Exact figures are not available but estimated to be 11%. Eczema is the most common reason for children aged 0-2 years consulting a family doctor (NICE, 2007)</p>	<p>An inherited inflammatory skin condition. Eczema comes from the Greek word "to boil"</p>	<p>Itchiness and scratching. Bleeding from lesions. Tiredness from disturbed sleep</p>	<p>Can include pollen, house dust mite, sand, water, animal hair, soap, modelling dough, food (tomatoes)</p>	<p>Reduced sensory play, for example, sand play. Tiredness can lead to lack of concentration. Unsightly skin can be a barrier to social interaction</p>	<p>Regular use of emollient creams to moisturise skin. Avoiding contact with triggers where possible. Vinyl gloves are sometimes used to help children access activities that can trigger a reaction</p>
<p>Epilepsy</p> <p>1:279 children affected (0.4%) (NICE, 2013)</p>	<p>Electrical impulses in the brain can trigger seizure. There are many causes of this condition and</p>	<p>Seizures</p> <p>Tiredness, lack of concentration, developmental delay</p>	<p>Avoiding or minimising known triggers e.g. emotions such as excitement, lighting</p>	<p>Lack of interaction</p> <p>Lack of concentration</p> <p>Requiring more</p>	<p>Medication</p> <p>Avoiding known triggers</p> <p>First aid knowledge when a child has a seizure</p>

Chronic condition and incidence	Description of condition	Signs and symptoms relevant to practitioners	Typical triggers in a setting	Possible impact on inclusion	Treatment
	commonly include brain damage, the result of an infection (such as meningitis) or genetic causes. Sometimes there is no clear reason			sleep	

Sources: Adopted and adapted from: Diabetes UK (2012) and National Institute for Health and Care Excellence Guidance (NICE) (2004, 2007, 2011, 2013a and 2013b)

Selecting the CHCs for this study was partly driven by the conditions that are included in the Managing Medicines in Schools and Early Years Settings Guidance (DfES/DofH, 2005) (the Guidance). Four of the five CHCs that have been selected for this study are included in the Guidance. The Guidance offers information to staff about the administration of medication to children with anaphylaxis, asthma, diabetes and epilepsy. These conditions are included in the Guidance because they are conditions "that most commonly cause concern in schools and settings" (p.25). However, the Guidance does not offer information about other CHCs that can affect young children. For example, it does not include information about eczema, which is a condition that affects a large number of 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. This implies that there is likely to be a significant number of children with eczema in day care settings. As well as affecting a significant number of children, eczema can have a profound effect on their lives (Van Onselen, 2009; Dawber, 2008). However, little is known about how the symptoms of eczema affect their ability to access their early childhood education. Therefore, eczema has been included as one of the conditions alongside the others in this study.

An overarching principle of the EYFS is acknowledgement that "children develop and learn in different ways and at different rates" (p.3). In the same sentence the EYFS acknowledges that children with special educational needs (SENs) and disabilities are likely to require extra support in order to be able to include them in their early childhood education. The symptoms of the conditions selected for this study are less likely to affect children in the same ways as those children considered to have a SEN or a disability, therefore

it is possible that the effects of these conditions may be over-looked and possibly under-estimated. This may be why children with CHCs are not addressed in the framework.

The research and field questions

An aim of this study is to contribute towards developing a theory of inclusive practice for children with CHCs. The over-arching research question asks "how do practitioners create inclusive environments in day care settings for children under the age of five with chronic health conditions?" The field questions examine the perspectives of practitioners, parents and children; the questions are:

- What are the effects of having a child with CHCs on parents and families?
- What are the effects of CHCs on children and how do the symptoms of CHCs affect their inclusion in day care?
- How do practitioners work with each other, and in partnership with parents, to include children with CHCs?

Whilst the aims of this study are to explore how practitioners make education and care inclusive for children with CHCs, it is important to point out what it does not aim to achieve. The study does not aim to give an in-depth description of each health condition, as this has been achieved elsewhere. Detailed information about each of the CHCs considered in this study can be found on the websites for charities associated with each condition. Further research will be needed to explore the fine detail of each particular condition and how the symptoms can affect inclusive education for young children.

The next section explains my positionality for investigating this area of research.

My positionality

My interest in this area of research has been formed from my personal and professional backgrounds. I am a Registered Sick Children's Nurse and have previously worked as a children's asthma nurse specialist. This has given me an insight into the effect on children and their families of living with CHCs. I gained personal experience of the effect of how asthma, anaphylaxis (a severe allergic response) and eczema can impact on children and their early childhood because my eldest daughter was diagnosed with these conditions about 26 years ago. The signs and symptoms of these conditions often created barriers to her being included in her early childhood education and sometimes in social events. When I became a teacher of ECEC, I became inspired by the wisdom of practitioners who were students on an Early Years Foundation Degree course. I taught them about the signs and symptoms of common childhood CHCs and they taught me how they would adapt activities to make them inclusive for such children. When I embarked upon my doctoral studies, I came to realise that including children in their early childhood education is an aspect of children's health that is under-reported in educational research. The education and care of young children under five is an area of personal and professional interest to me, therefore this study focuses on this age group. Consequently, my personal and professional interests have merged. I hope that attempting to develop a theory of how practitioners create inclusive environments for children with CHCs may have a transformative effect on the lives and education of such children (Clough and Nutbrown, 2007). This brief overview of my positionality will be expanded in more detail in the methodology section.

The next section summarises the aim of each chapter

Overview of chapters

Chapter 1: This chapter gives an overview of the aim of this research, which is to examine how practitioners create inclusive environments for young children with CHCs. It is important to appreciate that CHCs are different to complex medical needs and special educational needs (SENs).

Significant numbers of children are affected by CHCs (see Table 1.2). However the effects of the symptoms of CHCs on ECEC is an under-reported area of research.

Chapter 2: This chapter uses the EYFS as a framework for examining considerations and challenges that adapting the aims and principles of the EYFS present to practitioners. The literature review draws on medical, nursing and educational databases.

Chapter 3: This chapter explains the methodological choices made in the study and justifies the design of a Case Study using mixed-methods. My positionality is explored in detail using Brookfield's (1995) autobiographical lenses. The methodological choice of a praxeological approach is explained (Pascal and Bertram, 2012). The choice for this approach was based on the assertion that practitioners used their phronesis, i.e. their wisdom and experience, to adapt the aims and principles of the EYFS.

Chapter 4: This chapter explains the approaches taken to analysis of the data. The quantitative data was analysed using a group table (Denscombe, 2007, p.258). The qualitative data was analysed using an approach taken from Glesne and Peshkin (1992). Using this approach, the data was organised into four main themes.

Chapter 5: The first part of this chapter covers the findings from the quantitative data. The findings show that there were

a significant number of children with CHCs in the settings who participated in the study. The second part of the chapter explains how the rich and complex qualitative data is reported in the following 3 chapters. The main themes and sub-themes are summarised in Table 5.3.

Chapter 6: The effects CHCs have on the children and their families in this study are reported. The findings highlight the range of effects and suggest that understanding by practitioners of these effects is critical to the development of inclusive relationships with parents and children. This, in turn, is essential to creating inclusive environments for the children concerned.

Chapter 7: This chapter considers the importance of communication with parents, between staff in settings and with health professionals.

Chapter 8: This chapter explains how the EYFS poses some considerations and challenges for practitioners when adapting the aims and principles of the framework in order to create an inclusive environment for children with CHCs. Some of the findings report how practitioners used their pronesis to adapt activities. Particular tensions are highlighted concerning the provision of food in day care settings.

Chapter 9: This chapter highlights the responsibilities and qualities demonstrated by the practitioners in this study. The findings emphasise the importance of knowledge and training for practitioners, especially relating to the administration of medication for children with CHCs.

Chapter 10: This chapter discusses the main findings from this study. An important finding is the collaborative leadership skills that practitioners applied to the many challenges that creating an inclusive environment posed for

them. The findings emphasise the importance of the parents' role in working in partnership with practitioners to communicate information about the management of children's CHCs. The discussion concludes that the EYFS poses many challenges for practitioners who work to create inclusive environments for children with CHCs and their parents. The discussion examines how children with CHCs may be excluded from their education if parents and practitioners are not willing and able to work together.

Chapter 11: This concluding chapter returns to the use of Brookfield's autobiographical lenses to reflect on the messages that conducting this research has taught me and formulate suggestions for future research.

Chapter 2: Literature Review

Introduction to the literature

This chapter explores the literature that relates to the research question for this study. Literature is drawn from the two disciplines of health care and early childhood education and care; therefore databases using the following key words were searched:

- Children's health and wellbeing
- Chronic health conditions (CHCs) in children
- Early childhood education birth to three
- Inclusion in early childhood

The revised version of the Early Years Foundation Stage (EYFS) (DfE, 2012) has been used for this literature review to examine the considerations and challenges that the standards, aims and principles of the framework raise for practitioners who implement the EYFS for children with CHCs. The study explored the considerations made by the practitioners who participated in this study and how they adapted the framework for children with CHCs in order to include them in the curriculum. Although the EYFS creates a structure for the study, many of the issues that are discussed are relevant to practitioners who are educating and caring for children using other curricula.

The following sections in this chapter attempt to unpack each of these factors and explore them in the context of the literature. The aim is to examine the considerations and challenges that practitioners may have to address when adapting the EYFS in order to make early education inclusive for children with CHCs. The following headings have been

selected for this literature review to examine the aspects of the EYFS that practitioners may have to consider for children with CHCs:

- “Children learn best when they are healthy” (DfE, 2012, p.13)
- The welfare requirements of EYFS
- Personal, social and emotional development
- Including and supporting every child: current understanding of inclusion
- Inclusion of children with CHCs in education and society
- High quality early learning and staff qualifications, training, support and skills
- Playing and exploring in early childhood education
- Creating an enabling environment
- Positive relationships and the key person
- Partnership working with practitioners and/or carers

The next section turns to examining the aims of the EYFS for children’s health and wellbeing and examines the considerations and possible challenges for children with CHCs.

Children learn best when they are healthy

This section aims to examine what this statement means for children with CHCs. Health is a nebulous concept and it is difficult to define. This is partly because, as Underdown (2007) states, health is a personal experience and can mean different things to different families. As well as an individual’s interpretations of health, a person’s health may be influenced by where one lives in the world. For example, children in the developing world have different threats to their health than children who live in the developed world. Similarly, even though England is a part of the developed

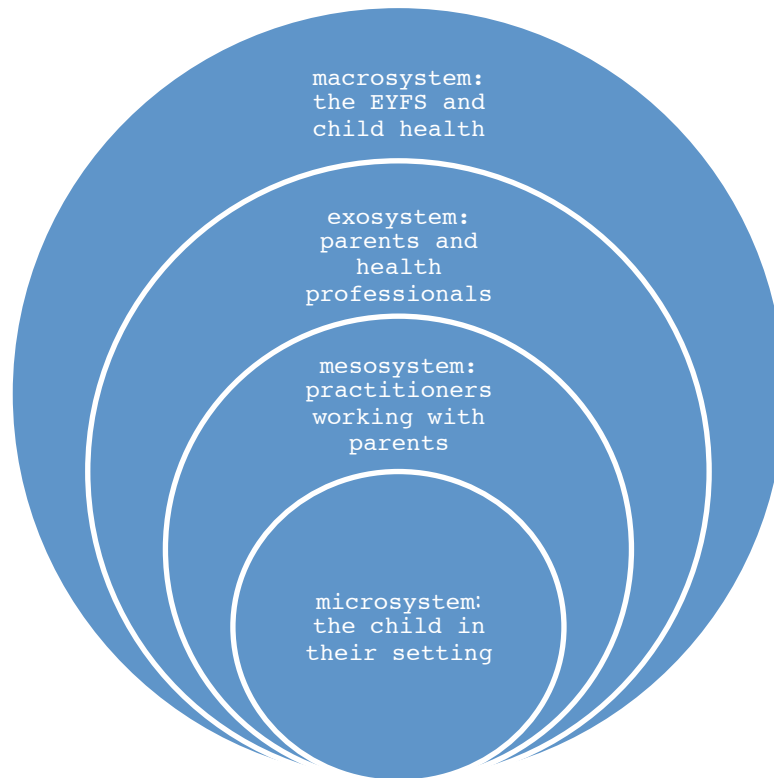
world, there are socio-economic, socio-cultural, religious and economic factors that can influence perceptions and experiences of health. It is worth bearing in mind that the CHCs considered in this study can occur in children from all socio-economic, socio-cultural and religious groups. Therefore, the effects of the CHCs can be an additional negative influence on health and wellbeing. These influences can make it difficult to decide on a universally accepted definition of the term 'health'. Nevertheless, the World Health Organisation (WHO) (1986) offers the following:

The extent to which an individual or group is able on the one hand to realise the aspirations and satisfy needs; and, on the other hand, to change or cope with the environment. Health is, therefore seen as a resource for everyday life, not the objective of living; it is a positive concept emphasising social and personal resources, as well as physical capacities.

I have highlighted the words 'to change or cope with the environment' because adults play a significant role in managing the environment to help children with CHCs to achieve optimal health. For example, practitioners in day care settings can make changes in the environment to minimise the triggers of CHCs.

To illustrate the inter-relationship between health and education and the roles of parents and practitioners working in partnership for children with CHCs in settings, I have drawn on Bronfenbrenner's (1979) ecological systems theory (see Figure 2.1).

Figure 2.1: Bronfenbrenner's ecological systems theory



The outer macrosystem in the context of this study is identified as the health and education policy in England for babies and young children. The information and understanding of how to manage the symptoms of CHCs may be held by parents, usually created with input from health professionals, in the exosystem. The mesosystem represents the role of practitioners who create an inclusive environment in the microsystem. Creating an inclusive environment may be partly achieved by working with parents. Therefore, in the context of this study, parents play a vital role as part of the mesosystem. They can be a conduit for information and knowledge from health professionals, who are another part of the exosystem, to practitioners. In turn, they can change the environment and help the child to cope in the microsystem. The inner circle represents the child in their education

environment and the ways in which the environment is managed can be a significant factor on the level of inclusion that children experience in their setting.

The following section discusses the link between health and wellbeing for children with CHCs.

The welfare requirements of the EYFS

The term welfare is synonymous with wellbeing (Oxford English Dictionary). As with health, the concept of children's wellbeing has become a focus of government policy and guidance. The National Institute for Health and Clinical Excellence (NICE, 2012), the National Health Service's evidence accreditation organisation, outlines in its Public Health Guidance for Social and Emotional wellbeing in the early years, the importance of good wellbeing for children. This guidance includes a number of factors that can impact upon children's wellbeing and children's health is one of them. However, it does not clarify what is meant by the use of the terms 'health' or 'healthy'. As previously stated, the symptoms of CHCs may result in children experiencing suboptimal or poor health. Feeling unhealthy or unwell can result in 'poor' (p.18) wellbeing, because of the effects of the symptoms of the conditions on children. A reduced sense of wellbeing may have implications for children's ability or desire to be involved with activities. As a consequence, they may not be included in the curriculum and this may affect their learning and development.

Assessing the level of wellbeing of very young children may be challenging. As previously mentioned, Laevers and Heylen (2003) measure children's level of wellbeing by observing the degree of their involvement in activities. In the context of this study, children with CHCs may be inhibited from becoming

involved with activities because of the symptoms of their condition. Therefore, their sense of wellbeing may be reduced as a consequence of suboptimal health and, in turn, this can have a negative effect on their learning. On the other hand, if they feel healthy, they have increased involvement in activities and a better sense of wellbeing. This suggests that close observation of children to identify their level of involvement in activities may be important in identifying how to promote maximum involvement with activities and minimal exclusion.

So far, I have attempted to explain the relationship between health, or more specifically, suboptimal health, caused by the symptoms of CHCs, and how they may affect wellbeing and involvement in learning and how this may result in exclusion. The next section discusses the link between health, wellbeing and social and emotional development.

Personal, social and emotional development

The EYFS has included social and emotional development as a prime area of learning and development. The NICE (2012) guidance links the concept of good wellbeing with positive emotional and social development. In an example of cross-governmental policy about young children's learning and development, the NICE guidance endorses the EYFS aim of providing "the building blocks for healthy behaviours and educational attainment" (p.33). It further adds that emotional and social wellbeing "provides the basis for future health and life chances" (p.18). The guidance goes on to support the EYFS approach to promoting social and emotional wellbeing. Therefore, it is relevant to explore the effects of the symptoms of CHCs on children's social and emotional development. For example, the effect of eczema is widely

reported as having a negative impact on emotional and social experiences (NICE, 2007). Lawton (2005) illustrates this point by stating that "eczema is a distressing condition that can severely impair self-esteem" (p.278). In turn, she claims that low self-esteem has implications for children's abilities to develop relationships with friends and family members. Her view is echoed by Shekariah, Kalavala and Alfaham (2010) who claim that an effect of eczema on children is low self-esteem and decreased participation in social activities. The reasons why eczema is cited as a negative impact on children's social and emotional development is not made explicit in the literature. However, this is possibly due to the fact that signs and symptoms of the disease cause pain and discomfort. Another consideration is that eczema is a visible condition, especially if it is present on areas of the body that are difficult to cover, such as the face or hands, which may also have an impact on children's participation in social activity.

Not surprisingly, children who have three or more CHCs concurrently are more prone to poor wellbeing. Waters, Davis, Nicolas, Wake and Lo (2008) claim that the presence of concurrent CHCs "significantly burdens children's health and wellbeing" (p.428). This is a salient point to consider for this study, because it is not uncommon for children to be diagnosed with a combination of asthma, anaphylaxis/allergy and eczema. This means that such children are more likely to experience poorer health and poorer wellbeing. In turn, poor health and poor wellbeing can lead to reduced social and emotional development in older children (NICE, 2012). Waters *et al* (2008) consulted the views of school age children, who had been diagnosed with asthma, allergies, diabetes and epilepsy, and their parents, to find out how they thought living with one or more of these conditions affected their lives. They found that the effect of sleep disturbance caused

by CHCs resulted in children reporting reduced feelings of wellbeing. This claim is illustrated by reports from parents of children with eczema who note that their children found sleep difficult because of persistent itching (Gill, 2006). Children with asthma can experience coughing at night, which can interrupt sleep (Levy, Weller and Hilton, 2006). Children with epilepsy who require medication are especially vulnerable to the effects of sleep deprivation and tiredness, as a consequence of the side effects of the medication (Anderson, 2006). Clark (2003) reported how older children with diabetes experienced nightmares when their blood sugar level went low, and consequently sleep disturbance can occur. Adequate sleep is essential for healthy brain development and deprivation can result in children being tired and irritable during the day. In turn, this can have an effect on children's emotional and social development (Lewis-Jones, 2006). Lack of sleep can also result in difficulties in concentration and this can affect children's cognitive development (Dahl, 1996; Meijer, Habekothe and Van Den Wittenboer, 2000). Therefore, it would appear that adequate amounts of good quality sleep for children is an important consideration for inclusion.

The majority of the research drawn from databases has involved school-aged children and their parents. This suggests that further research needs to be conducted in order to learn more about how CHCs affect children under the age of five. Understanding how to minimise the effects of CHCs may help to develop appropriate interventions aimed at promoting good social and emotional wellbeing for children in the early years of life. Greater awareness of how to adapt everyday activities for children may help to promote good wellbeing, and in turn promote inclusion.

The following section examines current understandings of inclusion and examines some of the reasons that CHCs are not widely considered in the discourse of inclusion. It also highlights some examples of how CHCs can impact on inclusion.

Including and supporting every child: current understandings of inclusion

The EYFS seeks "to provide equality of opportunity and anti-discriminatory practice, ensuring that every child is included and supported" (p.2). This statement is extended to emphasise the need to support children with special educational needs (SENs) and disability, and states that reasonable adjustments should be made to include them. The statutory framework requires settings to promote inclusive practice and value diversity and difference. However, the requirement to promote inclusive practice may be interpreted only in relation to SENs, and disability. This may be because the reasons why children and families are viewed as different or diverse are not made explicit in the EYFS. Also, the EYFS does not specify that children with CHCs require special consideration, even though practitioners aiming to implement the aims and principles of the EYFS may find there are challenges to inclusion for children with such conditions.

The association between inclusion and SENs and disability appears to have been partly shaped by social and government policy which aimed to demonstrate commitment to social justice (Paliokosta and Blandford, 2010). Petriwskyj (2010) supports the view that inclusion can be associated with identifying and meeting the education needs of children in compulsory education with disabilities and SENs. The reasons why inclusion continues to be associated with SENs and disability may be a legacy of previous legislation. The introduction of the Education Act of 1870 made education compulsory for

children who were regarded as educable. However, this inferred that some children were regarded as ineducable; an example of a health condition that resulted in children being regarded as ineducable was epilepsy. The Elementary Education (Defective and Epileptic Children) Act 1899 was introduced in order to segregate children who experienced epileptic seizures in their education setting, possibly to minimise the disruption caused by a child having a seizure in front of the rest of the class. However, having the other CHCs that are examined in this study were not, at that time, considered to be reasons for children to be deemed ineducable.

The Warnock Report (DES, 1978) brought a change in how disability was perceived. It helped to develop ways to integrate children, with conditions that may affect their education, into mainstream education. The Special Educational Needs Code of Practice (2001) was a further step in the development of the changing approach to identifying and meeting the needs of children with conditions that may be barriers to them accessing the curriculum. However, the Code of Practice did not name the CHCs in this study as being conditions that could result in children not being able to access the curriculum even though CHCs can equally disable an individual's ability to take part in daily activities. The Disability Discrimination Act (HM Government, 1995, section 1.1) describes a disabled person as "anyone with a physical or mental impairment, which has a substantial and long term ability to carry out normal day-to-day activities". Goodley (2011) suggests that disability leads to exclusion and people with disability are disabled by contemporary society. This results in disablism, which is defined by Marks (1999b, p.611, cited in Goodley, 2011) as "those times when the environment, body and psyche serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic

and political affairs" (p.9). These definitions of disability and disablism are pertinent to this study. As the research question for this study implies, practitioners who implement the EYFS standards, aims and principles have to bear in mind additional considerations and challenges to include children with CHCs. If practitioners do not adapt the environment so that it enables children to participate in the EYFS, children may experience disablism and they may be excluded from their early education.

The move towards the philosophy of inclusion has meant there has been a shift from SENs towards other considerations of what can make a child different or special. For example, Meighan and Siraj-Blatchford (2003) suggest that belonging to a minority group in society may result in exclusion from education. The Index for Inclusion (Booth, Ainscow and Kingston, 2004) was a major step in widening the scope of factors that can contribute to exclusion. The Index stated that inclusion should be viewed "as a principled approach to action in education and policy" (p.3) and encouraged practitioners to examine the culture of a setting and adapt the environment in order to promote inclusion. However, consideration of exclusive factors created by the effects of CHCs are not addressed in the Index for Inclusion.

Current understandings of inclusion are broader and Nutbrown, Clough and Atherton (2013) list a range of factors that are considered as possible "arenas for inclusion or exclusion" (box 2.1, p.9). However, CHCs are not explicitly mentioned as a factor that can lead to exclusion. Nevertheless, as outlined in Chapter 1, their assertion that "inclusion may be seen as the drive towards maximal participation in and minimal exclusion from early years settings, from school and from society" (Nutbrown and Clough, 2006, p.3) summarises the aim

of this study. This is because practitioners need to ensure that children are included in as many, or ideally all, activities in day care settings (i.e. they are achieving maximal participation).

The next section discusses the literature that is relevant to including children with CHCs in education and society.

Inclusion of children with chronic health conditions in education and society

So far, I have attempted to highlight that there is a lack of acknowledgement in the discourse of inclusion, and in legislation, that children with CHCs may require special consideration with regard to inclusion in their early education. This oversight is mirrored in the limited literature available that considers inclusion of children with CHCs.

There were two notable exceptions: an article by Mukherjee, Lightfoot and Sloper (2000) drawn from the British Education database; and, the findings of a study by Pitchforth, Weaver, Willars, Wawrzkowicz, Luyt and Dixon-Woods (2011) from a medical database.

Mukherjee *et al* (2000) report their findings from a study of primary and secondary school children with diabetes, eczema and asthma. Their findings concluded that teachers are a major source of support for such pupils, but the extent and quality of this support varied widely. There were several reasons for this variability that are relevant to this study. The first reason offered to explain the lack of consistency in support was linked to the variations in teachers' awareness and understanding of health conditions. For this present study, this point raises questions about practitioners' understanding and awareness of CHCs. It also raises questions

about how and where they gain knowledge and training to enable them to understand CHCs.

They offered that the variability of support in their findings was because of the teachers' perceptions of their role and responsibilities to pupils with CHCs. They go on to state that if a child has a condition "which prevents or hinders them from making use of educational facilities" (DfES, 2001, p.6), they receive a statement of special educational need. The main point of access for support is when they become the responsibility of the special educational needs coordinator (SENCO). However, children with the CHCs in this study are unlikely to be seen as having conditions that prevent them from accessing education. Their findings highlight the importance of practitioners recognising that the symptoms of CHCs can be barriers to inclusion. The findings also raise questions about how practitioners coordinate planning the EYFS to include children with CHCs.

Pitchforth *et al* (2011) report the experiences of 26 families with a child who had been diagnosed with nut allergy. The findings describe how parents of children with nut allergy become "alert assistants" (p.10) to create safe spaces to provide food for the child. These parents reported high levels of anxiety caused by needing to be constantly aware of food in the environment because it may be potentially fatal for their child with allergy/anaphylaxis. Some parents stated that they found it easier not to eat away from home because of their concerns. They described the restrictions caused by their children's dietary restrictions when eating away from home as akin to "a form of social exclusion or discrimination" (p.10). Similarly, Cummings, Knibb, King and Lucas's (2010) study of school-aged children with anaphylaxis to food reported the fear and anxiety they experienced when attending

parties and school trips. Their anxiety was because of the risk of food being present that may cause them to have an allergic reaction. These findings suggest that food and mealtimes are a source of anxiety to the parents of children with anaphylaxis as well as to the children themselves. Issues concerning the provision of food highlighted in these studies raise several points for consideration for practitioners in day care settings. For instance, the EYFS highlights the importance of providing healthy meals for children with dietary requirements. This includes ensuring the safe provision of food. For example, children with allergies must not be given food to which they are allergic and which may provoke a reaction. However, as Pitchforth *et al* (2011) and Cummings *et al* (2010) report, the provision of food is known to be a source of difficulty and potential exclusion for children with dietary restrictions. This raises the question of whether practitioners experience similar anxieties because of the responsibility associated with monitoring food for children with dietary restrictions. The need to create safe places for providing food to children with dietary restrictions raises the question of how mealtimes in day care settings are organised. For example, how do practitioners ensure that mealtimes are safely included in the social activity of eating? The children with dietary restriction in Cummings *et al's* study were of school age and were able to express their anxieties. However, it is not known if young children exhibit behaviour that suggests they are aware of potential difficulties associated with providing safe food.

So far, this section has examined some of the current interpretations of inclusion and issues that are raised in relation to this. It also examined why inclusion is an important subject for young children. Nutbrown and Clough

(2009) suggest that the inclusion of children in their early years settings and school helps to include people in society. However, they extend this view beyond the early years and argue that belonging to a group in society creates a sense of citizenship. Baker (2013) supports this view and claims that the EYFS is "an important pathway to develop active citizenship" (p.1). She makes this claim because of the emphasis that the EYFS places on Personal, Social and Emotional Development (PSED). Therefore, she proposes that the prime area of PSED can be used to promote participation in the social world of the early years setting and these skills can be used to develop greater civic engagement in later years in order to improve society. Baker warns that for this approach to work, "children need to be in a state of emotional wellbeing, feel secure and have a positive self-identity and self-esteem" (p.4). Therefore, in the context of this study, it is important that children with CHCs are enabled to be healthy so that they can engage with activities. In turn, according to Laevers and Heylen (2003), this will help them to develop a sense of good wellbeing, which in turn will predispose them to develop the skills that are essential for citizenship and being part of society in later life. The sense of belonging in the early years appears to influence an individual's ability as an adult to take part in society and make an economic contribution and therefore, create greater national economic success (Walker, Wachs, Grantham-McGregor, Black, Nelson, Huffman, Baker-Henningham and Chang, 2011). However, achieving these goals, as embedded in the principles of the EYFS, requires practitioners to be able to embed inclusive processes in the curriculum and pedagogy in order to help children to fulfill their potential (Nutbrown, Clough and Atherton, 2013). Achieving these goals is partly dependent on practitioners having the qualifications, training, support and

skills that are necessary to deliver high quality care that is tailored to the needs of children with CHCs. These points are discussed in the following section.

High quality early learning: staff qualifications, training, support and skills

The EYFS highlights the importance of high quality care for children. This section turns to examine the considerations for practitioners aiming to achieve high quality provision for children with CHCs. The discourse of quality is an evolving one and, according to Reed and Canning (2012), implementing quality is a continuous process and there are many facets that contribute to the discourse of quality. However central to implementing and delivering high quality pre-school education is the workforce. This is a point made in the Ten Year Child Care Strategy (HM Treasury, 2004), which links a high quality workforce with a highly qualified, graduate workforce. This view was reflected in a recommendation of the Nutbrown Review (2012) that an aim for government should be to create ways to provide “consistently high quality childcare” (p.4). The Effective Provision of Pre-School Education (EPPE) project (Sylva, Melhuish, Sammons, Siraj-Blatchford, and Taggart, 2004) found that high quality pre-school education is a fundamental influence on individuals being enabled to reaching their potential. Children who do not reach their expected developmental outcomes are less likely to reach their full potential and this can have a negative effect on the individual in childhood (Grantham-McGregor, Cheung, Cueta, Glewwe, Richter and Strupp, 2007). Walker *et al* (2011) extend this view and conclude that strong foundations laid down in early childhood have a lifespan impact.

Studies that examined children with CHCs and the effect of the quality of early childhood education were difficult to locate

in the literature. One exception is a study by Vernon-Feagans and Manlove (2005) who conducted research in day care settings on children in the first three years of life who had experienced chronic ear infections. The damage to their ears led to hearing loss and as a consequence, some children had social and language developmental delay compared to their peers. The findings concluded that high quality care in a supportive environment, with one-to-one intervention for children with practitioners, helped to compensate for the hearing loss and developmental delay associated with chronic ear infections. However, children with chronic ear infections in poor quality environments were deemed to be at the highest risk of poor developmental outcomes. Although chronic ear infections are not one of the conditions included in my study, Vernon-Feagans and Manlove's findings can be applied to practitioners who are supporting the needs of children with CHCs. For example, the quality of care could be indicated by the interventions practitioners need to make to create an inclusive environment for such children. Their findings suggest that practitioners can minimise the impact of the symptoms, or side effects, of CHCs by providing high quality care. However, their ability to do so may depend on their qualifications, training, support and skills. This is discussed in the following section.

The EYFS states that the quality of children's daily experience depends on "all practitioners having appropriate qualifications, training, skills and knowledge" (p.16). For practitioners who are creating inclusive environments for children with CHCs, qualifications that include knowledge of the specific CHCs is likely to be critical to their understanding of how to implement the EYFS and maximise inclusion. This point links to Mukherjee *et al's* (2000) assertion that the experience of school-aged children with

CHCs depended on teachers' levels of knowledge, as well the interest that they took in the children. Therefore, the reality of inclusion depended on the individual teacher and their personal commitment to the welfare of the child. Part of commitment to the welfare of children can be reflected in the qualifications, training, support and skills that practitioners have or demonstrate in their practice.

As well as qualifications, training that updates their knowledge and ability to administer medicines is an important consideration for practitioners. The EYFS states that settings must have a policy that aims to manage the administration of medicines safely. It also states "training must be provided for staff where the administration of medicine requires medical or technical knowledge" (p.22). Medication can come in a variety of forms. For example, liquid syrups, inhalers, injections or creams and are commonly prescribed in order to suppress or minimise the symptoms of CHCs. In addition to medical and technical knowledge, there is a need for practitioners to have in depth knowledge of the importance of the psychological aspects of medicine-giving. For instance, Clark (2003) discusses the importance of surrounding medicine-giving by a "playful ritual" (p.61) to help the child accept the need for medicine as part of their everyday life. This may be an important aspect of care for children to learn about from parents so that it can be emulated in the setting. However, in the absence of a playful ritual, the key person may be best placed to develop such an approach in order to gain the cooperation of children during medicine-giving. In turn, this will help to minimise the symptoms, which may help them to feel healthier, increase their feelings of wellbeing and enable them to take part in activities and be included in their setting.

So far, this section has summarised some key issues about the role of practitioners and how their qualifications, training and skills can help to equip them to deliver high quality care. The next section highlights some aspects of the curriculum that may require interventions by practitioners to make them inclusive for children with CHCs.

Playing and exploring in Early Childhood Education

This section explores the EYFS principle which states that “play is essential for children’s development... children learn by leading their own play” (p.6). Furthermore, the EYFS states that educational programmes must include activities that enable children to explore and play with a wide range of media and materials. A play-based curriculum raises considerations for practitioners adapting play in order to make them inclusive for children with CHCs. The belief that young children learn through a pedagogy of play is a view that is influenced by Piaget’s (Piaget and Inhelder, 1969) theory of cognitive development which suggests that children learn and develop their intellect through sensorimotor experiences. The aspects of play that will be discussed in this section are sensory (or messy) play and outdoor play.

Moyles (2012) offers a contemporary view of the importance of messy play as a valuable way of offering learning opportunities to young children. She suggests that the use of activities that include open-ended materials, which are resources that have no pre-determined uses (Drew and Rankin, 2004). Examples of open-ended substances include water, sand, modelling clay, shaving foam and food, such as jelly. Engagement by children with such substances can stimulate their creativity and offer them the opportunities to explore. Such experiences can help children to make discoveries and can

enhance cognitive skills. Drew and Rankin go on to state that promoting children's creativity is helpful in promoting greater competence in children. Therefore, the sensory, or messy, play that practitioners include in their planning in day care settings are important for young children's learning. However, all of the substances mentioned above can be common triggers for asthma, anaphylaxis and eczema. To illustrate this point, Figure 2.3 shows a child engaging with a messy play activity that uses shaving foam. Figure 2.4 shows a photograph of the hands and arms of an individual with eczema. It is probable that children with eczema would find the contact with shaving foam on their skin an intolerable experience. Therefore, adapting messy and sensory activities for children with CHCs may pose a challenge to practitioners.

Figure 2.3: Child engaging in messy play with shaving foam



Figure 2.4: Image of person with eczema - photograph obtained from Wikipedia



Messy play photograph used with permission from Susanne Axelsson

Turning to considerations about outdoor play, the EYFS requires practitioners to provide daily outdoor activities and ensure that "outdoor activities are planned and taken on a daily basis" (p.24). Outdoor play can offer opportunities for physical activities that can contribute towards the development of physical and mental wellbeing (Wood, 2013). For example, physical movement helps to increase the amount of calories that are used by the body. This reduces the risk of becoming obese which can help to promote good wellbeing for individuals which, as previously discussed, has implications through the life span. Pellegrini, Dupuis and Smith (2006) point out that the amount of physical play that children engage with is at its highest peak during the pre-school years. They further suggest that young children are predisposed to physical, or locomotor play. Pellegrini and Smith (1998) highlight the link between physical play and intellectual development. Therefore, if children are inhibited from outdoor and/or physical play, this may be a disadvantage for their development. For example, Pellegrini *et al* (2006) suggest that children who engage with physically

vigorous play, such as rough and tumble play, exhibit decreased levels of aggression. Therefore, children who are inhibited from such activities because of the symptoms of CHCs, may be at risk of developing aggressive behaviour.

Wood (2013) identifies some considerations about inclusion for children in outdoors spaces, for example issues about gender and culture. However, being outdoors and engaging in outdoor play may be problematic for children with certain CHCs and may result in exclusion for them. For example, the airways of children with asthma can be sensitive to the temperature changes that are experienced as a consequence of moving from a warm room into a cold outdoor area. As well as temperature change, physical exercise can trigger asthma symptoms and both examples could mean that a child experiences an asthma attack. Uncontrolled asthma that results in an asthma attack is an unpleasant and a potentially fatal experience (Levy *et al*, 2006).

Moreover, the symptoms of diabetes can be challenging when planning outdoor play involving physical activity. For example, Riddell and Iscoe (2006) stress the importance of physical activity for children with diabetes to prevent long-term complications of the condition in later life (heart disease is an example of this). However, they also caution that there are practical considerations associated with planning safe physical exercise for children. The considerations include the need to balance the intake of carbohydrate and insulin dosage with the "timing, mode, duration and intensity of exercise" (p.16). Clearly this approach requires specialist knowledge to achieve safe physical exercise, but the point is included to highlight some of the complexities that must be addressed to make outdoor physical play activities inclusive for children with diabetes.

An aim is to provide physical activity with few limitations "so that they can derive the social, psychological and physiological benefits of a physically active lifestyle" (p.23).

These examples highlight that there may be limitations imposed upon children with CHCs because of the possibility of triggering symptoms that can have unpleasant side effects. Parents and practitioners may impose restrictions on children's activities for this reason. However, another question to consider is how children respond to activities that may exacerbate symptoms and whether they exclude themselves from valuable learning activities. Restrictions on children's play activities as a consequence of the symptoms of CHCs may have wider implications for children's development as well as their sense of wellbeing. This again highlights the importance of this study to help understand how practitioners modify factors such as the physical environment and daily activity to include children with CHCs.

The next section discusses some of the issues that practitioners may have to consider when creating an environment that enables inclusion for children with CHCs.

Creating an enabling environment

The EYFS states that providers need to create "enabling environments" (p.3) in which children can learn and develop well. It also states that "premises and equipment must be organised in a way that meets the needs of children" (p.24). Creating an enabling environment for children with CHCs requires consideration by practitioners to make the microsystem inclusive for these children. For example, the symptoms of asthma, eczema and anaphylaxis can be triggered by animal hair, dust and pollen, all of which may be present in

day care settings. Salo, Sever and Zeldin (2009) researched the levels of allergens in day care settings and found there were significant levels in bedding and soft toys. This finding illustrates the need to have a rigorous cleaning regime for the premises. Such cleaning extends to putting soft toys into a freezer compartment to kill house dust mites (Levy *et al*, 2006) because this reduces the presence of this allergen, thus reducing a trigger in the environment. The EYFS suggests that a way that children can learn understanding of the world is by observing animals. Their observations of animals can help them to make comparisons and appreciate differences and similarities (Linfield, 2013). Observing animals may also help children to gain an understanding of how to care for living creatures. Consequently, some settings may have pets such as guinea pigs, but practitioners may not have considered that hairy animals can be a trigger for the symptoms of asthma, eczema and anaphylaxis. Reducing the presence of animals in the environment may create a tension for practitioners, because removing animals because of the possibility of their hair provoking an allergic reaction for some children may disadvantage children who are not allergic to them.

This section has touched on some of the considerations that practitioners need to bear in mind when creating an enabling environment. The next section changes direction and discusses the relationships that need to develop so that inclusive environments can be created for children with CHCs.

Positive relationships and the key person

One of the overarching principles of the EYFS is that “children learn to be strong and independent through positive relationships” (DfE, 2012, p.3). This reflects the findings

from neuroscientific research (Gerhardt, 2004) that states that children thrive emotionally by experiencing high quality relationships with other people, primarily their parents. In the absence of their parents in a day care setting, the role of a key person is viewed as vital for the child's emotional wellbeing and development (Elfer, Goldschmied and Selleck, 2003). The development of the relationship between a key person and their key child requires time and understanding for them to form a dyad where they are tuned into each other. However, there may be difficulties associated with CHCs that are problematic for the development of a positive relationship. For example, as stated earlier, sleep deprivation resulting in excessive tiredness may cause children to be irritable (Gill, 2006). Another example of a difficulty as a result of behaviour caused by CHCs is that a child with eczema may dislike being held because of the attendant discomfort and this may also cause irritability. If a child dislikes being held, it may mean that the child is denied the opportunity of "snuggling in" (David, Goouch, Powell and Abbott, 2003, p.63) with their key person in order to gain physical and emotional comfort. An irritable baby may be difficult to please and this may result in the key person questioning his or her ability to soothe the child which in turn could cause resentment on the part of the practitioner.

It must also be acknowledged that eczema can be a disfiguring skin condition, and Gill (2006) challenges nurses to examine their willingness to have physical contact with children who have unpleasant-looking skin because of eczema. This has an implication for practitioners who are required to have close physical contact with their key children and they too may find contact with eczematous skin a distasteful experience. This clearly raises important issues for inclusive practice in early childhood settings.

These examples aim to illustrate issues that may affect the relationship of children with CHCs and their key person developing in a positive way. According to Page (2011), babies in day care settings need professional love from their caregivers. If such relationships do not develop because of the difficulties outlined above, and babies are not benefitting from the professional love of their key person, this may impact negatively on the holistic development of the child. In turn, this may mean that the child is being denied inclusion in their setting. However, issues pertaining to relationships do not stop with the child and include other people, especially parents. The next section discusses the considerations for practitioners who work to create inclusive partnerships with parents.

Partnership working with practitioners and/or carers

Froebel, in the nineteenth century, championed the belief that educators should work closely with parents (Tovey, 2013). In contemporary times, the EYFS seeks to provide "partnership working between practitioners and with parents and/or carers" (p.2). However, the discourse of practitioners working with parents is an evolving field of research and little is known about how parents and practitioners work in partnership to create inclusive environments for children for CHCs. Reasons given for the importance of practitioners working with all parents include the need to care, protect and advocate for children (McDowall-Clark, 2012). All of these reasons may resonate even more so with parents of children with CHCs. 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). 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 or curriculum. Therefore, parents can be the bridge between children's exosystem and the microsystem (see Figure 2.1). This requires parents to have resources to fulfil this role and this may be especially challenging for marginalised and disadvantaged parents (Field, 2010), this point will be returned to below.

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, according to Brooker (2010), 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, Garralda and David'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 of children with CHCs may 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. Page (2010) describes the dilemmas faced by the mothers in her study as they make decisions about childcare. She reports the anxieties they experienced because of leaving

their children to be cared for in an out of home setting. It is likely that mothers of children with CHCs will have additional dilemmas and anxieties about the ability of practitioners to care for their child.

The literature from the health databases revealed some insights into the experiences of parents living with children with CHCs. Some of these will be discussed further to highlight additional considerations for practitioners to address when establishing relationships with parents. Edwards and Titman (2010) point out that some parents and children will be more resilient to the impact of living with CHCs than others, so it should not be assumed that all parents experience the same emotions. On the other hand, Gillespie, Woodgate and Chalmers (2007) report high levels of emotional responses amongst parents caring for a child with a CHC. For example, Bowes, Lowes, Warner and Gregory (2008) state that the "chronic sorrow in parents of children with type 1 diabetes is so profound that it was likened to a grief reaction akin to a bereavement" (p.992). Such feelings continued for years after diagnosis. This study also reported parents' on-going feelings of upset when they watched their children having, or had to give their child, their insulin injection.

Anxiety and fear were other emotions reported by parents. For example, mothers of children with potentially fatal food allergies described how they found it difficult to relax when their child was away from their supervision (Gillespie *et al*, 2007). A similar fear is described by the parents of a two year old girl, whose asthma symptoms were provoked by the emotion of excitement. She became excited at playgroup and the only way that they felt they could avoid her having an asthma attack was for her not to attend playgroup (Nocon and

Booth, 2001). Thus she was excluded from accessing crucial early years education. The literature therefore suggests that 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, Carpenter, Gillaspay, Cheek and Page, 2007).

The parents' position in the mesosystem (Bronfenbrenner, 1979) means that they have a crucial role in gathering relevant information from health professionals regarding the management of their child's CHCs. Parents will also have information about how they manage their child's CHCs at home. This information will be important for practitioners to understand how to develop inclusive education for children. Therefore, parents will need to have the resources to convey the information to practitioners. Such resources include an ability to understand how to interpret such information. Therefore, parents are likely to need a level of understanding of spoken and written language. As previously mentioned, marginalised and disadvantaged parents may not have the resources available to fulfil their role in the child's mesosystem. This resonates with Knowles and Holmstrom's (2013) view that Bourdieu's (Bourdieu and Passeron, 2000) notion of social and cultural capital is associated with increased levels of educational achievement. Knowles and Holstrom argue that parents who have "stores of social capital" (2013, p.21) are more likely to provide knowledge and understanding that help to promote their children's development and learning. This implies that, for this study, if parents have knowledge and understanding of their children's CHCs, they will have greater ability to know how to manage the condition. In turn, this will help to promote

their children's learning and development and, consequently, increase their educational achievement. Developing stores of social capital may be challenging for marginalised and disadvantaged parents who perhaps lack the social and educational capital to fulfil this aspect of their parenting role. Therefore, as Knowles and Holmstrom point out, the interpersonal skills and knowledge of practitioners will be even more vital in order to be able to manage chronic CHCs and work with parents in a way that is inclusive.

Conclusion

The review of the literature has considered some of the current interpretations of inclusion in the UK. It appears that inclusion in early childhood education has positive benefits not only for children's learning and development, but also for adults across an individual's lifespan. The literature has reported some of the benefits associated with learning through play, in particular with messy and outdoor play. Children having access to inclusive early education is thought to develop citizenship in adulthood, therefore this has a positive benefit to society. An example of how early childhood education promotes citizenship includes social activities such as eating and developing relationships. However, the review of the literature has highlighted many considerations and some challenges for practitioners who work with the EYFS and it indicates that there are significant aspects of the framework that need to be adapted to make education inclusive for children with CHCs. In particular, the review has highlighted many considerations for children with eczema. As previously, speculated, this is possibly because the symptoms of eczema are visible.

The literature reviewed suggests that the EYFS's aim to include and support all children may mean that inclusion in England appears to be about finding ways for the child to fit in with the existing curriculum and environment (Bertram and Pascal, 2002). In contrast, in New Zealand, the Te Whatu Pokeka project (New Zealand Ministry of Education, 2009) has been developed. This is so called because a pokeka is a Maori blanket made of flax and woven in the inside of the blanket are albatross feathers which protect the child, providing warmth, comfort and security. The blanket takes the shape of the child as it grows and this individuality is reflected in how the curriculum is determined and shaped by each child. The "Te Whatu Pokeka" philosophy is of inclusion for 'children with difference'. In this study, the differences are caused by the symptoms of CHCs that require adaptations to the curriculum. Te Whatu Pokeka may be a more suitable philosophy to adapt for an early years curriculum. This analogy reflects my vision of how practitioners can learn about how each child is affected by their CHC. It also reflects my vision of how practitioners can work in partnership with parents to adapt the environment and curriculum so it fits the child and reduces the impact of exclusive factors that may lead to disablism.

Despite the limited literature focusing specifically on the factors raised in my research question, there are numerous issues regarding the inclusion of children with CHCs in ECEC, and there is a clear need to understand how practitioners address such issues. The challenge for me as a researcher was to find out how they created an inclusive environment for such children. The next chapter sets out the methodological choices I selected in order to explain why I approached my study in the way I did.

Chapter 3: Methodology and Methods

Introduction

The purpose of this chapter is to explain and justify the methodological choices and research methods I selected for this study. It will also reflect on methodological issues that I have encountered whilst conducting my research. The chapter begins with an exploration of my positionality for this research and also examines my reflexivity as a researcher. I then examine these issues from the four perspectives of my life that have shaped my motivation for this research. These perspectives are as a nurse; a mother; a teacher and a researcher. I begin with a discussion on what is meant by the term 'being an ethical researcher'. This is an important consideration for all researchers, but given the sensitivity of the topic of his thesis, this was a particular concern for me.

Becoming an ethical researcher: reflexivity and positionality

This research was designed to explore how children with CHCs are included in the aims of the EYFS and central to this study is my desire to conduct research that is ethical. Ethics can be viewed from a regulatory perspective and this includes the procedure of appraising ethical considerations relating to the research as laid out by BERA (2011) and applying for permission from the University to conduct the research (University of Sheffield, 2010). However, ethics do not fit neatly into one section of my thesis. This is because ethical considerations are embedded in every step of the research process and for me this started prior to deciding on my research question. Canella and Lincoln (2007) remind us that

part of becoming an ethical researcher requires the researcher to ask "how do I assemble myself as an ethical researcher?" (p.326). I became aware that a starting point in assembling myself as an ethical researcher began as I identified my positionality in relation to the research. My interest in the research question is informed by professional and personal interest. Ely (1991, cited in Possick, 2009) suggests that research projects are interwoven with the researcher's deepest, social and professional passions and commitments. Ely's assertion resonated with my view about my research. Each perspective raises different ethical considerations and I have reflected deeply on the possible ethics of decisions that I have made during the course of this research. These perspectives are inextricably linked and in order to explain my positionality and give context to my study, each perspective is addressed in the following four sections.

From the perspective of a nurse

After qualifying as a general nurse, I trained as a children's nurse in order to continue to learn more about children and their health. I worked for three months on a cardio-thoracic ward and throughout this period was particularly involved in the care of a child who I shall call Joshua (featured in Figure 3.1) who was 14 months old and was a patient on the ward. Joshua had cystic hygroma, a condition that causes cysts to grow. In his case, they had grown around his airway and he had a tracheostomy to keep his airway patent and avoid the possibility of him not being able to breathe. This was 1982 and there were no services available in the community to care for children who had a tracheostomy, therefore Joshua lived on the ward.

Figure 3.1: 'Joshua' and me in 1982



Children like Joshua in contemporary society would be eligible to have the services of the community children's nursing service (Department of Health, 2011). Such services aim to plan care for children with long-term conditions so that they can "live as normal a life as possible" (p.18) and be included in society. When, in June 2011, I came across the photograph in Figure 3.1, taken in December 1982, I was writing the proposal for my thesis and my thoughts were focused on how I was going to articulate my reflexivity in relation to my research question. This photograph made memories of Joshua come vividly to life. It stirred memories of this period of my nursing life and I realised that I had never forgotten Joshua. He was a lively and affectionate little boy and I can remember that when he wanted a cuddle, he would put his arms up and wail for attention and ask to be picked up. I remember being troubled about Joshua and his abnormal life as a healthy boy on a busy surgical ward being passed around to whichever

nurse happened to have a few spare minutes to give to him. The photograph made me reflect on Joshua's early experience and I realise how research, policy and practice has progressed over the last thirty years and developed current understandings of what is now called the concept of inclusion.

Joshua's experience was not unique because there were other children who lived in the hospital. Reflecting on Joshua's situation, I realise that some of the roots of my interest in inclusion were established at this time. His experience of living on the ward was a stark example of a child missing out on early childhood education. However, his situation has made me think that children with CHCs in contemporary society, in educational settings, may still be excluded from activities and experiences that other children participate in.

Later in my nursing life, I worked in the community as a paediatric asthma nurse. Asthma is an atopic condition, which means that it is an allergic condition; children who have asthma may also have a combination of other allergy related conditions such as eczema, hay fever and allergy or anaphylaxis. All of these conditions have a range of symptoms that require management in order to minimise or remove them. However, gaining control of the symptoms can be difficult to achieve and all of these conditions can have impact on the quality of life of children and their families. I remember some of the consultations with parents who were in despair because their children's asthma symptoms were not under control. One of the most troublesome symptoms seemed to be when the children had a cough at night, which disturbed their sleep, and in turn kept their families awake as well. Another aspect of CHCs that was of concern to the parents I saw in my asthma clinic was the amount of times that their children became unwell. Viruses are the most common trigger for asthma

symptoms. These children missed many days of school during the winter because their asthma was provoked by viral illnesses and I wondered what the effect was on their education.

My nursing perspective has informed my research interest because I became aware of how health, or suboptimal health, can impact on children's and families' lives. As a consequence, this can lead to children being excluded from aspects of education and society. Corbin (2008) states that her previous work as a nurse still influences her research because she wishes to develop knowledge that will guide practice. I concur with Corbin's wish to do the same and recognise that my nursing experience is a significant influence on my research. An aim of the findings will inform and guide a theory of inclusive practice for children with CHCs.

From the perspective of a teacher

Brookfield (1995) encourages the use of an autobiographical lens in order to critically reflect on being a teacher and to understand how our experience informs our teaching. I am aware that my experience as a nurse for children (and their families) has informed my teaching, and in turn, my research. I started teaching child health modules to Early Years Foundation Degree students in 2005. The assessment for the module required students to select a child with a medical condition and then to examine the effect the condition had on the child's learning and development. The students were required to identify barriers to inclusion because of the condition and then to evaluate their role in supporting and including the child and family. I discussed with students how the symptoms of CHCs could impact upon the care and education

of young children. I learned how these experienced practitioners changed or adapted the environment to minimise the symptoms of CHCs to accommodate the needs of children with CHCs and to include them in activities.

When I asked them how they started the process of doing this, they would often be dismissive of what they had achieved and say "it's just common-sense, isn't it?" This pragmatic approach by the students may be an example of what Greenwood and Levin (2005) describe as 'phronesis' which is wisdom derived from experience (p.51). In addition, Thomas (2010) offers: "the Aristotelian notion of phronesis is about practical knowledge, craft knowledge, with a twist of judgment squeezed in to the mix" (p.578). Thomas's definition captures the essence of how I became interested in exploring my research and field questions. This is because what the practitioners expressed was not simply common sense. I interpret what they describe as common sense, as their wisdom, derived from their experiences of adapting the curriculum and environment in day care settings for young children with CHCs. Practitioners used their wisdom and applied knowledge to their practice, thus using their judgment, as Thomas suggests, so that an inclusive environment could be created for children.

As a higher education teacher, I made suggestions of literature from the fields of health, inclusion and education for students to draw on for their modules. However, as previously mentioned, there was very little literature available that examined how symptoms of CHCs may impact on early childhood education. Thus, I realised that the conversations I had during the teaching sessions had elements of what Thomas described as "surprise, intelligent noticing and serendipity" (p.579). These conversations led me to

conclude that there was a gap in the literature that I could help to fill with my research.

From the perspective of a mother

The perspective that caused me most concern, with regard to the ethicality of this particular research, evolved from my personal perspective as a mother. I was troubled that my deep interest in the care and welfare of children with CHCs and the reasons for my interest may cast scepticism on the trustworthiness of my research. In order to explain my concerns about my research question and to highlight my reflexivity, this section summarises my positionality for this research from the perspective of being a mother.

My personal interest in the welfare of children with CHCs developed as a result of being the mother of my eldest daughter, Nicky, who was born on Mothers' Day in 1987. She developed eczema at the age of five months, and was diagnosed with anaphylaxis to nuts at eight months. She developed asthma when she was fourteen months. At the age of six, she was diagnosed with Coeliac Disease, which meant that she had to have a gluten free diet in order to stay healthy. The symptoms of these four CHCs meant that she had periods of ill health, pain and discomfort from birth. Nicky died on the 20th of February 2006, the month before what would have been her 19th birthday. Her life and mine was influenced, but not necessarily overshadowed, by the potential threats to her existence of the symptoms of the CHCs she lived with every day. For instance, there were frequent newspaper reports about people dying from anaphylaxis to nuts. As previously discussed, I had worked as a nurse with a specialism in the care of children with asthma, so I was acutely aware that asthma is potentially fatal. Therefore, when she died many

people assumed that the cause of her death was related to the anaphylaxis that ingesting nuts caused, or alternatively, an asthma attack. The cause of her death was, in fact, dilated cardiomyopathy, which was thought to be viral in origin. However, the exact reason for her heart becoming enlarged and unable to function normally is largely speculative. One suggestion is that Coeliac Disease, which is an autoimmune disease, can have a negative impact on the immune system. A weakened immune system, in combination with large doses of steroids and antibiotics which she had throughout her life to manage the symptoms of anaphylaxis, asthma and eczema, left her vulnerable to contracting a virus that damaged her heart muscle causing the condition that led to her death. The heart is unable to continue working and eventually stops in a way that the cardiologist described as "being like turning off a light switch". Nicky's death was sudden and unexpected and I hope it was painless. Nicky's medical history is complex and according to the cardiologist whom my husband and I consulted in order to test our other two daughters' hearts for a genetic link (which was not the case), may be unique.

The reason why this aspect of my positionality troubles me is linked to my decision to interview parents of children with CHCs in order to explore their experience of working with practitioners to create an inclusive environment for their children in day care settings. At the point where I was formulating my research question, my professional and personal influences had not been unravelled to examine them from the four perspectives that I have identified. Canella and Lincoln (2007) remind us of the need to be aware of "examining how this personalising of our work affects those around us" (p.329) and this reminder was useful to me to reflect and identify my interest from the perspective of a mother. Because I had experienced the anxieties of living with a child

with potentially fatal chronic conditions, I did not want to ignite or reinforce fears in parents who were participants in my research. I was concerned that parents may want to know why I was so interested in this aspect of children's health and I troubled over my response if faced with such a question. However, this concern abated when I realised that sharing the other three perspectives that inform my research question are justifiable reasons for my interest. My concerns have been unfounded because none of my participants have asked me why I am interested in my research question. This may suggest that some of my anxieties about answering the question were linked to my emotions about responding to questions that explain my research interest from the perspective of being a mother to Nicky. However, acknowledging my reflexive positions has enabled me to "reduce the risks to the trustworthiness of the research and transform threats into opportunities to enrich qualitative data analysis" (Possick, 2009, p.859).

In order to demonstrate from a mother's view what having a chronic condition can mean to a child and the family, I have included some memories of my daughter's life. I remember sports days at school, often a warm and sunny summer's day. The high pollen count and sitting on the grass in the sun was a combination of triggers for Nicky's eczema. The pollen got into her already cracked and vulnerable skin resulting in angry, red, wheals, which made it clear why eczema is from the Greek word meaning "to boil" (Gill, 2006, p.494). The weals would then become intensely itchy and the scratching she did in response to the intense itching, meant that she ran her race with blood pouring down her legs.

In the 1990s, nut allergy was being diagnosed more frequently and there was a great deal of media interest in the subject. When Nicky was nine, there was a newspaper report suggesting

that vegetable cooking oil may contain nuts and therefore should be avoided by people who were allergic to nuts. On holiday in Majorca that summer, we went out for lunch to a restaurant. We had the usual discussion with the waiters about the ingredients of the food we wanted to order. However, the Spanish waiters were not very convincing about their understanding of the importance of the answers to our questions about whether the food contained nuts. Nicky usually enjoyed eating and therefore I was surprised when she refused to touch any of the food brought to our table. It turned out that she was terrified that the chips may have been cooked in oil that contained nuts and therefore was potentially dangerous. She was genuinely terrified of the possible consequences. I can remember trying to explain to the rest of our family that eating food when she was not confident about its safety, and could be potentially fatal, was akin to taking the risk of stroking a venomous snake. I can remember Nicky's relief when I told her that we would buy and prepare all of our food in the villa that we had rented for the remainder of the holiday. This decision helped avoid the anxiety that was brought on by what Pitchforth *et al* (2011) describe as being an "alert assistant" (p.10) to create safe places for food for children with anaphylaxis to nuts.

I remember dropping Nicky off to other children's birthday parties after she had been diagnosed with coeliac disease with a lunchbox of gluten-free and nut-free food. Children's birthday parties can be fraught events and I did not want Nicky's dietary requirements to become a barrier to her being invited because of the mother's anxiety about having to make alternative dietary requirements. In addition to this, I felt less anxious if I knew that Nicky had her own food to eat when away from me.

As Nicky became older and left her early years behind, she developed a pragmatic approach to living with her CHCs. She sometimes tried to find solutions to barriers to taking in part in activities, but on other occasions she would simply get involved and suffer the consequences afterwards. This was especially true of her work as an artist; the use of pastels and other art media would frequently trigger eczema symptoms, but her desire to draw and to be creative was stronger than the consequences of the painful effect that could be the aftermath of using pastels. However, it is her early years that have had the greatest impact on my motivation to explore how CHCs are managed in early years settings. In fact I can remember Nicky's skin specialist advising me to send her to pre-school because it was a good idea for children with eczema to have something to occupy them because it took their minds off scratching.

These specific examples from Nicky's life highlight some of the difficulties that she faced daily as a consequence of living with the symptoms of CHCs. As her mother, I frequently had to advocate with practitioners, teachers and other parents on her behalf in order to adapt activities so that she could be included. The experience I gained from being Nicky's mother has made me realise how important it was for her to have parental involvement in her care and education. For this reason, the opportunity to include the parents of children with CHCs is part of the study design.

Over the last two years my professional and personal interests in how CHCs can impact on the lives of children and their families have converged and have resulted in my research question as a focus for my thesis.

From the perspective of a researcher

The convergence of my experiences as a nurse, mother and teacher informed the research question for this study. I became aware that the students' phronesis about inclusive practice for children with CHCs was under-researched and further research was required in order to highlight the under-rated impact that CHCs can have on children and their education.

My experience of bereavement initiated by the sudden death of a much-loved child, is mirrored by Alice Terry (2012) who describes her feelings following the sudden and unexpected death of her 29 year daughter as having "someone ripped from your world. An action of immediate severance beyond our control... this immediate severance has hurled me into an unfamiliar... world" (p.355). The 20th February 2006, the day that Nicky died, started a period of time in my life that can be described as the start of an unfamiliar world for me too. Terry recorded her journey in grief via an auto ethnographic study, grounded in reflective inquiry in order to give insight borne of a mother's experience of loss. Her reflections from her grief journal were the basis of her study. She describes her first step away from "the belly of the whale" (p.359) which is how she describes the private place where she carried out the physical act of grieving into the public place of returning to university teaching. I can concur with Terry's description of leaving the belly of the whale and making a conscious decision to return to my teaching post in order achieve the same as Terry; which was to shift "my focus from my grief to teaching" (p.359) in order to have a distraction from my grief.

Terry relates her desire to turn her feelings of grief into something more positive, and again, I can concur with her

desire to somehow use the emotions in a positive and productive way. Becoming a researcher has given me the opportunity to have a purposeful way of using my experience that I have gained from the four perspectives in a positive way. As my research study has developed, I am aware that my experiences of having a child with CHCs has raised questions for me that have not been answered, and these have become some of the research questions embedded in this study. Finding answers and helping to improve practice for children with CHCs will demonstrate my epistemology that there is a need to be aware of the health needs of children with CHCs so that early childhood education is inclusive.

However, I am acutely aware of the importance of acknowledging that my interest does not lead me to analyse data and draw conclusions that may be overtly influenced by my positionality. I am mindful of Cannella and Lincoln's (2007) warning "to recognise the professional as the personal while at the same time examining how this personalizing of our work affects those around us" (p.329). In addition to being aware of the ethical considerations in relation to the participants, I was aware that being a mother to a child with several CHCs, the research may have an impact on me. Possick (2009) encourages us to be aware that research that is influenced by autobiography can be an emotionally intense experience for the researcher. Exploring the lives of my participants could have been a source of distress to me, but this was not the case.

Having considered my reflexivity and justified my positionality, the next section considers my research question.

Selecting the research question

A research question "is the engine which drives the train of enquiry" (Bassey, 1999, p.67). The dearth of literature relating to how CHCs can affect children's access to early education opportunities suggested that it was an under-explored area. This meant that the scope of the research could be too big for a small-scale study. In order to generate a question that is answerable within the limitations of the resources available to me, I applied the "Russian Doll Principle'" (Clough and Nutbrown, 2007, p.37). As previously stated, there are many CHCs that affect children and could have been included. However, as anaphylaxis, asthma, diabetes and epilepsy are included in the Managing Medicines in Schools and Early Years Settings Guidance (DfES and DofH, 2005), they were included. Eczema is not included in the guidance, but as previously stated, this condition affects 11% of children aged between 6-18 months (NICE, 2007). This implies that eczema has a significant impact on children's health, a view informed by my experience as a mother and nurse, and therefore is included in the study. Applying the Russian Doll Principle helped to refine a manageable question by helping to limit the number of CHCs to be researched. However, the literature review suggests that some of the effects on children and families are common to many CHCs, for example sleep disturbance, or the need for children to have medication. Therefore, this study aims to find general themes to highlight issues relating to inclusion for such children who may have different CHCs. Therefore, the research question is: "How do practitioners create inclusive environments in day care settings for children under the age of five years with chronic health conditions?"

Selecting participants

The research question seeks to find out how inclusive environments are created for children with CHCs. This could have been examined from the sole perspective of practitioners. However, parents and children have also been included. As previously mentioned, parents are the links between home and the child's setting. As Brooker (2011) suggests, ensuring that practitioners work with parents to create this link is an intricate process. For children with a CHC, the transfer of information from medical professionals to parents and on to practitioners is an additional layer of complexity; therefore, not including parents would be a significant omission from the study.

The justification for including children links to Lahman's (2008) assertion that "children are always Othered or unfamiliar in research" (p.282). I felt that it was important to ensure that a child was familiar, rather than being invisible in this research. The voice of the child in educational research has become increasingly important, however there are considerations to be borne in mind when attempting to listen to the voice of the child. Lahman also comments on "the disheartening... dearth of methodological resources in relation to research with children" (p.289). Since Lahman documented her view, there has been increasing attention given to methodological issues relating to research with children in order to examine children's perspectives on their own lives. An example of the growing literature is Fargas-Malet, McSharry, Larkin and Robinson's (2010) article, which describes the "methodological shift" (p.175) which has been created as a result of different views of children which now views children as "experts in their own lives" (p.175). The view that children are capable of being active

participants has meant that there has been an emergence of participatory research methods, informed by the view that research should be with or for children, rather than on children. However, much of this literature relates to children over the age of three. Therefore, I decided that the aim of exploring a child's perspective was not to convey the voice of a child with CHCs, but to explore and relate the experience of a child with a CHC in a day care setting in order to explore how he/she is, or is not, included in the education and microsystem of the setting.

Locating a paradigm for the study

The study has many of the elements of a praxeological research approach. Pascal and Bertram (2012) define praxeology as follows:

praxeology describes the theory and study of praxis (defined by Freire, 1970) as '*reflection on, and in, human action*', and embeds this in a situated context in which power and ethics are fundamentally realised and explored in an attempt to engage in participatory practice to better understand human actions, and in our view, to transform them" (p.481).

Praxeological research is, according to Pascal and Bertram, the theoretical construction of knowledge by combining phronesis with praxis. This approach was a useful paradigm to meet the aims of this study because, as previously discussed in the section about my positionality, part of my inspiration for this study was gained from Foundation Degree students, who interpreted their phronesis as common sense. The concept of phronesis can also be applied to my interpretation of the research question. As a nurse and a mother, I have acquired knowledge of some of the difficulties that children with CHCs endure. As a result of my knowledge of early childhood education, I was able to identify that the Foundation Students

who were experienced practitioners had used a phronetic approach to do what they regarded as common sense. In addition to this, my research question was derived from what Thomas (2010) refers to as "understandability emerging from phronesis – in other words, from the connection to one's own situation" (p.579). Therefore, I was making a connection between the practitioners' phronesis and practice and my knowledge and, in doing so, I identified a gap in the literature that my research question is aiming to address.

Praxis can be defined as "theories of action'" (Pascal and Bertram, 2012, p.480). This is a useful definition to consider in the context of this study because it reflects the thought that practitioners invested in how to adapt activities to make them inclusive for children with CHCs. They then translated their thoughts into action by adapting activities. However, there is no theory that reflects practitioners' praxeological approach to how inclusive environments are created. This claim is made because there is limited research in the education databases that explicitly examines how CHCs can interfere with young children's everyday activities. There is also a lack of research that examines how practitioners adapt the EYFS in order to include these children in the framework. However, anecdotal evidence suggests that practitioners have developed their own theories of action in order to adapt the EYFS to make it inclusive for children with CHCs. Therefore, adopting a praxeological research approach will help me to explore how practitioners have achieved, or developed, inclusive practice. My intention is to promote awareness of this issue so that a theory of inclusive practice can evolve to include children in early education and transform their lives. However, these intentions require researchers to engage closely with

reflexivity as well as rigorous selection and justification of research decisions.

Having devised the research question and decided which participants were going to help me answer it, I needed to select an approach that was going to allow me to collect diverse sources of data. As Yin (2009) states, the use of a case study enables the researcher to be flexible and responsive. Therefore, a case study approach was deemed the most appropriate for my study.

Case study approach

This section discusses the reasons for selecting a case study approach. As well as including a justification of this choice, it will consider some of the advantages and perceived disadvantages of this approach.

Stake (2005) uses the term instrumental case study to describe a case that is examined in order to provide "insight into an issue". He goes on to say that "the case is of secondary interest... plays a supportive role, and it facilitates our understanding of something else" (p.445). Stake's definition lends itself to justifying the selection of a case study for this research because the exploratory nature of the research question intends to give insight into the issue of how practitioners adapt activities and the EYFS framework to create inclusive environments. This is an important aspect of children's care that can have profound pedagogical implications if they are excluded from their early education. Thomas (2010) says that an advantage of a case study is that its use "offers an example from which one's experience, one's phronesis, enable one to gather insight or understand a problem" (p.578). Thus the selection of praxeological research using a case study approach is justified.

Bassey (1999) asserts that case study is a tool that “can be a prime research strategy for developing educational theory which illuminates policy and enhances practice” (p.111). As discussed previously, some practitioners have developed inclusive practice for children with CHCs. Therefore, their practice may be disseminated as a consequence of this study in order to enhance inclusive practice to a wider audience. This quote summarises an aim of this study because, as already discussed, the effect of CHCs on inclusion in early childhood education is under reported in educational research. As well as a paucity of research, current child health policy tends to be focussed on early intervention for specific conditions (Department of Health, 2004), rather than on the management of CHCs. Consequently, the considerations that practitioners have to bear in mind when they are adapting the EYFS to make it inclusive are invisible from policy. An example of a recent policy proposal that has been withdrawn was the proposal to increase the ratio of children to practitioners in day care as proposed in More Great Childcare (DfE, 2013). The decision to withdraw this proposal is pertinent to practitioners who create inclusive environments for children with CHCs. This claim is made because the symptoms of CHCs can be controlled by adapting the environment and/or by the administration of medication. However, both of these approaches require extra time for planning, as well as for meeting the care needs of children with CHCs. The data and findings about time and ratios are reported and discussed in later chapters.

Denscombe (2007) highlights the suitability of adopting a case study approach when the researcher is investigating what Yin (1994) describes as a phenomenon that occurs naturally. Therefore, a case study enabled me to research how the triad of children, parents and practitioners worked together to

adapt the environment so that children who live with the effects of CHCs can access their early education. Bassey (1999) also proposes that adopting a case study approach can test a theory. Therefore, a case study is justified for this research because no theory exists as to how practitioners implement the EYFS in an inclusive way.

A criticism that is frequently levied at the use of a case study approach is that it is not possible to generalise from a single case. However, Ruddin (2006) disagrees, saying that "it is inaccurate to conclude that one cannot generalize from a single case" (p.802). However, the intention of this research is not to make generalisations drawn from a single exploratory case study, but to offer an understanding from the view of practitioners, parents and children. The data may help to create knowledge and contribute to forming a theory of how inclusive environments can be created. The case study can illuminate an under-researched and over-looked aspect of early childhood education. Other researchers may wish to emulate the design of the case study to explore the same research question.

Recruiting participants

Having decided to include parents, children and practitioners as participants, I then had to decide how to determine the scale and scope of the research and how to select participants. Bearing in mind that trustworthiness is a criticism that is levied at the use of case study approach (Bassey, 1999), it was important to ensure that the design of the case study was methodologically sound in order to increase the trustworthiness of the findings. An example of how

trustworthiness was considered in relation to the recruitment of participants is discussed in the following section.

Because I had a professional relationship as the teacher of some of the potential participants, I decided to approach all of the day care settings in the Borough with whom my college placed early years students for their practical experience and not solely student alumni. This was beneficial to the methodological rigour of the research design for two reasons. Firstly, I understood that previous students who were approached directly by me to be potential participants may have felt pressured into participating (I was also concerned that they may have felt that I was testing them about their knowledge in some way). Secondly, I felt that it was important to maximise the opportunity of exploring the perspectives of participants who had not been students on the Foundation Degree at the college where I had worked and therefore had not studied the child health module with me. Therefore, I felt it was important to design a study that distanced me as a researcher from the practitioners, because they may be former students, during the stage where participants were being recruited. However, as I was working full time it was a practical consideration to select participants who were geographically close by to where I live in order to minimise travel time and make the best use of limited time available for research.

As the results from the data revealed, the most common CHCs that affect children in day care settings are allergy/anaphylaxis, asthma and eczema. The other conditions of diabetes and epilepsy are under-represented from within the case. In order to explore some of the issues relating to inclusion for a child with diabetes, an interview with the parents of a two-year-old boy diagnosed with diabetes, from

outside the case, has been included. Data relating to the family from outside the case is clearly identified.

Defining the boundaries of the case

Denscombe (2007) points out that "adopting a case study approach is a strategic decision that relates to the scale and scope of an investigation" (p.37). This point linked well to my research question because I wanted to select enough participants in day care settings to explore my research question. The Local Authority description of the Borough is summarised as being:

broadly affluent with contrasting neighbourhoods... two neighbourhoods are in the 5% of most deprived areas in the country... 11% of the total population is Black and Asian ethnicity... which is less diverse than England as a whole (name of borough removed to protect anonymity, (People and Places, 2011)).

It was hoped that there would be a response from settings that were from affluent and deprived areas in order to represent aspects of economic and racial diversity.

Part of the Case Study design included a postal questionnaire, which was sent to all of the sixty settings in the Borough. I was aware that it was unlikely that I would receive a 100% return rate, however, I did not wish to make the selection of which settings to survey because of the reasons I have previously outlined. Selecting the Borough's day care settings as the boundaries of the case meant that "a purposive sample" (Stake, 2005, p.451) was being selected. In turn, from the respondents to the survey, a smaller number of participants would be identified who would give "opportunities for intensive study". The selection of the participants in the case were small, but as Stake also says a small sample can

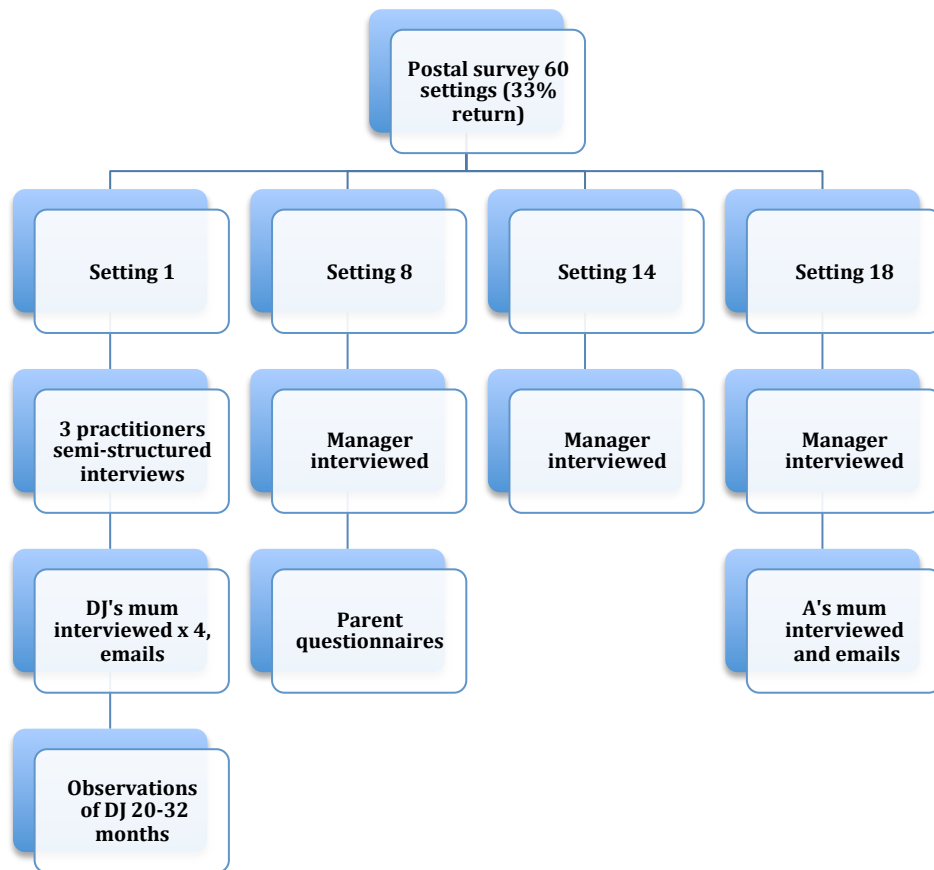
offer “epistemological opportunity” (p.451) to learn important findings from a small case.

Having selected the location of the case and defined the case, it was important to determine what I wanted to find out from the case. I realised that there was an opportunity to gather a wide range of data in order to answer my question and this required the use of quantitative and qualitative data.

Research Design

This section starts with a diagram to illustrate the case study design (see Figure 3.2). This includes details of the methods used and the participants in the case.

Figure 3.2: Summary of the design of the case study



The following sections explain and justify the choices made for each element of the research design.

The use of mixed methods to gather quantitative and qualitative data

This section aims to justify the selection of a case study approach using mixed methods in order to collect quantitative and qualitative data for this small-scale research. Hall and Ryan (2011) propose that:

The case study is well suited for qualitatively driven mixed-methods research because the case study approach can be oriented toward engagement with lived experiences and the complexities of contexts at multiple levels (p.107).

Hall and Ryan's proposal lends justification to the selection of a case study approach using mixed methods. This is because the research question aims to gain an understanding of how many children with particular attributes there are in day care settings. It also aims to discover how practitioners address the complexities of adapting the EYFS to make the aims and principles inclusive for children with CHCs. These points will be discussed in more detail in the following sections.

Justification for selecting quantitative data

Silverman (2007) urges us to consider the place of using a quantitative approach in order to find out the scope of a problem. As previously stated, the numbers of children in the UK who have been diagnosed with one or more of the conditions are increasing (Waters *et al* (2008)). Therefore, it is possible that there are a significant number of children with CHCs in day care settings. However, the scale of this number is not known. An example of why it is important to have a more accurate indication of the numbers of children with CHCs is the afore-mentioned government aim to increase the ratio of children to practitioners in day care settings (DfE, 2013). Having an understanding of the amount of time that practitioners indicate that they spend in managing the symptoms of CHCs in order to create an inclusive environment may be important. For instance, if a child needs a significant amount of extra time spent on managing the symptoms because of medication that needs to be administered, this may be a reason to increase the adult ratio for children who require extra care. On the other hand, if meeting the needs of children with CHCs requires extra time, and extra time is not reflected in increased ratios of adults to children, this may become a deterrent to day care settings offering a place to such children. If children are not offered a place as a consequence of their CHC, this is

exclusive because children are potentially being denied access to early education. Therefore, the use of quantitative data is a justified choice for this study.

Justification for selecting qualitative data

Adopting a qualitative approach to this study mirrors an approach by researchers in the field of nursing, such as Sartain, Clark and Heyman (2000), who use qualitative methods of research find out how CHCs impact on children's life experiences. The use of qualitative data for this research is justified because the findings gave me an insight into the effects of CHCs on children's lives in day care settings. In turn, the stories of practitioners, parents and children informed my understanding of how inclusive environments are created. Corbin and Strauss (2008) suggest that researchers are drawn to this approach because of their characteristics. One characteristic is curiosity, and I concur that I am extremely curious to find out answers to my questions. However, Corbin and Strauss's view that qualitative researchers "enjoy serendipity" (p.13) strikes a chord with me as well. As will be discussed below, there were several serendipitous moments that have shaped the course of the research and this will be reflected upon in the conclusion to my thesis.

Methods used in the case study

The use of a case study was a useful approach to gather data in order to answer my research question because, as Bassey (1999) suggests, it offered flexibility to go down other relevant avenues of data collection. For instance, the parents who were interviewed offered to email me with any other thoughts that they had about their children. This was an opportunity that they all offered at the time of being

interviewed, so I was able to add this to the consent form at the time of interview.

Postal Survey - questionnaire

The method selected to gather quantitative data was to survey the 60 settings identified for the case study in order to explore the numbers of children with CHCs in day care settings (as explained earlier). A questionnaire was designed (see Appendix 3) and it was piloted with the help of undergraduate students who had experience of being on placement in day care settings. The feedback from the students was useful in order to identify potential ambiguities and correct mistakes. The final version was printed on yellow paper to make the questionnaire stand out so that busy practitioners were more likely to locate it. The questionnaire included inductive research questions that were exploratory in nature. For example, Question 1 and 2 aimed to gain an understanding of the number of children who had been diagnosed with the CHCs that are the focus of this study. The questionnaire and an accompanying letter (see Appendix 2) explaining the purpose of the research, and a stamped-addressed envelope, were sent by post to the named manager of each setting. The aim of collecting the answers to the questionnaire was to gather data that provided a foundation and a context for the qualitative aspect of the study.

As Denscombe (2007) points out, a survey has the useful purpose of identifying willing respondents who could volunteer to become participants in the qualitative aspect of the study. Approximately one third of the questionnaires were returned (19 out of 60), which is a number in line with what Denscombe suggests is a valid response rate. Twelve of these respondents indicated that they were willing to participate

further in the research. The next stage of the study involved semi-structured interviews with practitioners.

Semi-structured interviews

Selecting semi-structured interviews as a research method was an opportunity to gather thick, qualitative data, which gave "the story behind the numbers" (Shaw, 2003, p.66). Fontana and Frey (2005, state that interviews are not neutral tools of data gathering but rather active interactions. They go on to state that if the interviewer adopts an empathetic stance, this can create a partnership between the interviewer and interviewee to produce results that can be used. I had considered a range of ways to collect data, these included diaries and video recordings. However, I recognised that practitioners and parents are busy people and I wanted to adopt a method that gave them minimum disruption to their lives, as well as giving me the best chance of collecting as much valuable data as possible. An interview schedule was created (see Appendix 4) and the questions were based on themes that arose from the literature review as well as reflections on the practitioners' phronesis. The questions were designed to be open-ended and invite as wide a response as possible, but the schedule, which was used for all participants, meant that there was a consistency to the questions and this was designed in order to help analysis of the data.

The semi-structured interview schedule was piloted prior to being used. Again, an undergraduate Foundation Degree student who was an experienced practitioner responded to the questions and gave feedback to help with clarifying the structure of the schedule. Semi-structured interviews (Appendix 6) were also used for two mothers and for the family from outside the case. The parents were asked if an interview was a suitable method

for them prior to the meeting, to which they all agreed. The questions were sent to parent participants ahead of the interview.

The interviews were recorded using a digital recorder and transcribed by myself; a methodological choice to help me to engage with the data. The transcripts were member checked with the interviewee. This process was explained to them at the end of the interview and again in email correspondence that accompanied the transcript. The email correspondence generated another source of useful data, though I should stress that permission was sought from the participants before using the data (this point is covered in the ethics section).

Practitioners as participants

Table 3.1 is a summary of information about the practitioners who participated in the study. The information includes pseudonyms used and details of when the interviews were conducted. The table includes details of the settings and the relationship of the practitioner to me.

Table 3.1: Summary of practitioner participants interviewed in study

Date of data collection, Name (all are fictional) and role in setting	How practitioners were recruited to contribute to study	Description of setting	Relationship to researcher
May 2012: Joan: Manager in Setting 1	Offered to be interviewed after being contacted	90 children. Part of a chain in an affluent area	Known to me as a student placement provider
June 2012: Maria: Deputy Manager in Setting 8 and key person to Freddie	The Manager of the setting volunteered Maria's time	70 children. Privately owned. Most parents working	Student alumnus

Date of data collection, Name (all are fictional) and role in setting	How practitioners were recruited to contribute to study	Description of setting	Relationship to researcher
June 2012: Mary: Manager in Setting 14	Offered to be interviewed after being contacted	Setting 14: 84 children. Privately owned setting on a school site	Unknown to me prior to research
March 2012: Joint interview with Sharon and Charlotte: Manager and Deputy Manager in Setting 18	Offered to be interviewed after being contacted	85 children in an area of social deprivation. Privately owned	Student alumnus
April 2012: Becky: Key person to DJ (child observed as part of the study) in Setting 18	Manager suggested that I interview her and she agreed	As above	Student alumnus

Parents as participants

All parents were unknown to me prior to the research. Table 3.2 summarises details of the parents, the research methods used and their relationship to the children. A detailed account of how the parents were recruited is included below.

Table 3.2: Parent participants

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 Setting 2
June 2012: 30 minute semi-structured interview plus emails from Freddie's mum	Mum to Freddie (who has eczema and asthma) in Setting 4. She came and met me at the setting during her lunch break to be interviewed
4 x 30 minute interviews,	Kate (pseudonym). Mum to DJ (who has

Research method	Relationship to setting and children in the case
plus emails March 2012 – March 2013	asthma, eczema and dietary restrictions) in Setting 18. 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 (child who was not in pre-school education). John's parents invited me to their home for the interview

Children and families as participants

This section gives a profile of the children and their families who participated in the study.

Child 1: 'DJ' was 20 months old at the start of the study and 32 months at the end of data collection. DJ has been diagnosed with allergies, asthma and eczema. DJ, his mum and dad and his twelve year old sister live together. His ethnic origin is Afro-Caribbean. His sister and mum have allergies, asthma and eczema. His mum worked as a practitioner in a different room in the same setting. Data included observations of DJ over the period of a year, interviews and emails with his mum. Details of how DJ and his mum were recruited to the case are included below.

Child 2: 'Freddie' was 33 months at the time of the interview with his mum. Freddie had been diagnosed with asthma and eczema. He lives at home with his mum, dad and his fourteen year old brother. His ethnic origin is white British. Freddie's mum's workplace is ten minutes from the setting. I did not ask to observe Freddie, because I had decided that a prolonged period of in-depth observations on one child may be more beneficial to the findings of the research so I chose to concentrate on DJ.

Child 3 from outside the case: 'John' was 34 months at the time of the interview with his mum and dad. John had been diagnosed with insulin dependent diabetes 21 months before the interview. His ethnic origin is white British. John lives with his parents; his mum is a student early years practitioner (formerly a paramedic) and his dad is a paramedic. Details of how John's parents were recruited to the study are included below.

Ideally, I would have liked to recruit more children to observe with a range of conditions. This is a limitation of this study, but it could be a focus of further research.

Observations

Observations were selected as the research method to explore a child with CHCs in a day care setting. Fargas- Malet *et al* (2010) assert that observations have a long tradition as a method of researching young children. This tradition is continued in the EYFS (2012) which places observations as the starting point for learning about children. Pascal and Bertram (2012) encourage researchers who are adopting a praxeological approach to take risks and to go beyond orthodox research methods and to consider the use of drawings and other participatory techniques. However, there would be limitations to choosing such a technique to convey the voice of the child because the age range that is being explored in this case study is under five. Therefore, the use of discussions with a child, or examination of drawings created by very young children or babies, would be limited.

I was anxious to adopt a method that would produce data to help to answer my question. I did try to seek literature to find alternative ideas of how researchers have used different methods with very young children but unfortunately could find

none at the time. However, it was important to include a child's perspective in my study and it was essential to adopt a method that could give insight that would be methodologically robust. Therefore, I made the decision to include observations of one child.

Selection of a child to observe: 'DJ'

After deciding that a series of observations of one child would be a useful approach to help answer my research question, the next stage was to recruit a suitable child. The manager and deputy manager of Setting 18 had agreed to participate in the next stage of the study and they were the participants for the joint interview. They also agreed to approach parents whose children had been diagnosed with CHCs to find out if they were willing for me to observe their child in the setting. After the interview, the managers invited me into the toddler room so that I could meet the staff and children. I was keen to introduce myself to the staff and inform them about my research and find out if they were willing for me to pay a series of visits to observe a child. At this point, the managers had mentioned the names of three children who they thought would be suitable for the aims of the research and whose parents were likely to be willing to consent to observations and be interviewed. There were three members of staff in the room and a lady who was introduced to me as 'Kate', I was told that she was a member of staff in the pre-school room, she was sitting with a small boy on her lap. We all sat on the floor with the children and I summarised the aims and explained the rationale of my research. The practitioners were asking me questions about my research and appeared interested and keen to be involved in the research. Kate had sat quietly, nodding as she listened to the conversation. She then said, gesturing to the small boy on her lap "this is my son, he has asthma, eczema and allergies

to foods, I can see exactly what you are getting at, I have what he has got and so has my daughter. I am more than happy for you to observe him and for you to interview me". At a later date, Kate told me that she was not at work that morning, but she had called into the setting for a few minutes with DJ to complete an errand. She had gone into the toddler room because DJ had indicated that he wanted to go in to the room. She said:

You are really lucky that I was there, I don't work Fridays and I don't work in that room, I had just dropped in. I want to take part because I know how important it is for people to understand more about how children like DJ are affected by these conditions (Research Journal entry 23rd March 2012).

I view Kate's unplanned presence in the room that day as an example of synchronicity, which according to Jung (1973) is when events have "meaningful coincidences" (p.xi). Kate had the phronesis of both an experienced practitioner and a mother of two children with three CHCs. She also had personal experience of living with CHCs. Reflecting on the selection of a child for my study, I realise that Kate selected me, rather than me selecting her son as a participant in the study. From the start, Kate was an enthusiastic supporter of my research, and her phronesis informed the course that my research took. For example, I noted in my research journal:

Kate suggested that I observe DJ regularly over a period of time in order to observe the impact of the seasons on him. She is a really knowledgeable woman and speaks about her children's and her own conditions with authority (Research Journal entry 17th March 2012).

I was aware that Kate's decision to volunteer herself and DJ as participants required further considerations of the ethics because of her position as a practitioner in the setting, as well as being DJ's mother. I was also aware that the managers needed to support this decision. After a confidential

conversation with the managers, they reassured me that they were happy for Kate and DJ to be participants.

Observations of DJ

I was mindful of Kate's suggestion about observing DJ over a period of time to identify if the weather and seasons affected the symptoms of his CHCs. I extended this suggestion to observing him at different times of day. The aim of the observations was to gain global data about DJ and gain a snapshot of his life in his microsystem. Clark and Moss (2011) advocate the use of observations as a piece of their mosaic approach to watch how children spend their time in a setting. In turn, the art of watching can be used to gain a view of what it is like for a child in their setting. I especially wanted to note DJ's choices of play activities, as well as finding out what meal times were like for him and to note if the symptoms of his CHCs were evident and if they affected his participation in activities. Having been given the privilege of permission to observe DJ, the next decision was to decide how to observe him in order to capture data that would help me to answer my research question. Pascal and Bertram (2012) assert that the use of observations is key to understanding the experiences of children in day care. The observer can use their senses to absorb the events occurring in the child's environment. In addition, the observer can use their body as a conduit to make connections between what is being seen and the theory or meaning that underlies the actions. The use of observations can be for the greater good of promoting knowledge about children and, in the context of this research, the data from the observations may inform findings that can contribute to a theory of inclusive practice for children with CHCs.

Selecting an observation tool

I was familiar with the range of observation methods available, for example narrative, time sampling and tick charts (Riddall-Leech, 2008), but I was not sure of the approach that would be the right one for the aim of my observations of DJ. In order to inform my decision about which technique to use I made a familiarisation visit to the toddler room in order to consider my position in the room as researcher. I was aiming to ensure that my presence would create minimal disruption to the usual running of the room. However, during my visit, many of the other children were deeply interested in my presence, and were keen to interact with me. This had implications for the choice of observation method to be used. I could not adopt an approach that meant I was focussed solely on DJ because I would not be able to acknowledge and interact with other children. Therefore, a narrative approach for lengthy periods of time was not going to be suitable. A method that avoids long narrative but has short and sharp periods is the Effective Early Learning (EEL) (Bertram and Pascal, 2006) programme observation sheet. The EEL approach advocates that 5 minute observations are taken every 20 minutes. A recording sheet was completed for each series of observations. The date and times were recorded and kept in order to add to the audit trail of data.

Summary of observations of DJ

Table 3.3 summarises the periods of observation of DJ over a year. Attempts were made to visit as often as possible in order to observe him. However, DJ's times in his setting and my availability were constraints that dictated the amount of time I was able to observe him. Nevertheless, I attempted to spread the observations during the seasons and at different

times of the day in order to consider a range of factors that may impact on him. Very quickly, I realised that meal times were of particular interest, so attempted to be present at this time in order to observe him.

Table 3.3: DJ's observations timetable

Observations 'DJ' 20-32 months	Used the EEL Child tracking observation sheet – 5 minutes every 20 minutes
2 nd March 2012	Familiarisation visit
23 rd March 2012	1200-1500
30 th March 2012	1200-1515
26 th April 2012	1400-1800
24 th May 2012	0915-1215
27 th June 2012	1300-1500
4 th November 2012	1015-1300
21 st March 2013	0900-1230

Other sources of data

Semi-structured interview with a family of a child from outside the case: John and his parents

As previously stated, John is a child from outside the case. John's mum is a student practitioner at a university where I had visited to give a lecture on child health. The focus of the lecture was exploring how children with CHCs can be excluded from their early education because of the symptoms of

the condition. My research proposal for my doctorate was included as part of the lecture. Following the lecture, John's mum approached me to say that some of the discussion resonated with her experience as a mother of a child with diabetes and she offered to be a participant. Our discussions that day emphasised to me the appropriateness of my choice of research question. At this point, I was aiming to harvest a participant with diabetes from the postal survey. I would have preferred to use the case study design, because I felt it was a robust methodological approach. However, the postal survey revealed that there were only two children with diabetes and both of them were in the same day care setting. Furthermore, the practitioners had not volunteered to be involved with the next stage of the study. Therefore, six months after our initial conversation I approached her via email to invite her to participate.

The percentage of children aged 0-4 years who have diabetes is 4% (Diabetes UK, 2012). However, it is difficult to extrapolate this figure in order to find out the probable number of children that one would expect to find within the case. However, the low number of children with diabetes in day care may mean that their diabetic care needs are problematic for practitioners and therefore children with diabetes are being excluded from early education. As Gorard and Smith (2006) point out, as researchers, we need to be aware of not only the willing participants in research, but to consider who does not participate. The paucity of children in day care settings with diabetes may mean that they are not accessing day care settings for some of the reasons that John's parents disclosed during the semi-structured interview. The experiences of children who are living with CHCs, such as diabetes, appears to be invisible from early childhood educational research. Therefore, including an interview with

John's family was an attempt to give voice to him and his family. John's story, as told by his parents, is a story of their lives since John became unwell and diabetes was diagnosed. The reason for including him and his family was to investigate the effect that diabetes has had on their lives and John's early education. The method that was used can be described as an emancipatory interview approach. Lawthom (in Goodley, Lawthom, Clough and Moore, 2004) suggests that the use of emancipatory interviews give the interviewee the opportunity to gain something from the product of the interview. In the case of John and his family, his Mum's wish was to highlight the difficulties that she encountered when trying to find a suitable day care setting for him. Lawthom concedes that the use of emancipatory interviewing needs to be considered, because the researcher always gains from the participation and the researched gains less. There is an added dimension to the use of an approach that aims to emancipate people in society. Emancipation implies that there is equality between relationships. However, as somebody who was employed to teach John's mum, there needs to be an acknowledgement of the relationship between teacher and student. Murray and Lawrence (2000) remind us about the responsibilities of being a teacher and researcher. They point out that when researching with students, there will always be an imbalance of power, with power being in the favour of the teacher. However, the relationship between John's mum and myself was less that of teacher and researcher and more like two individuals interested in highlighting the care and education needs of children with CHCs.

Semi-structured interview in the family home

I was invited to John's family home by his mum on the 7th June 2012 and conducted a semi-structured, one hour interview with John and his parents. The questions were sent to his mum

prior to the interview (see Appendix 6). The interview was digitally recorded with their permission and subsequently transcribed by me. The transcript was sent by email for member checking by John's mum. In addition to the data from the interview, John's mum emailed me after the interview and some of the content of that correspondence was useful data. She gave consent for the data to be included in the study.

Ethical Considerations

The regulatory procedure of completing a research ethics application form was submitted prior to approaching participants or collecting data (University of Sheffield, 2010). Approval was granted for my study (see Appendix 1). The approval was granted with the proviso that the participants must not include people who were National Health Service employees. The ethical considerations were not confined to the regulatory procedure, because my awareness of the need to be ethical was on-going. For example, I continued to examine my reflexivity in relation to how my four perspectives could influence what I heard or saw in a way that could challenge the trustworthiness or academic rigour of my findings. However, I soon realised that capturing my thoughts in a research journal helped me to grapple with these issues. During the planning stage of my study, I was reminded by Bassey (1999) of the necessity of ensuring systems were in place to make assurances about the trustworthiness of the study. I drew on Bassey's interpretation of Lincoln and Guba's (1985) concept of trustworthiness in order to illuminate "the ethic of respect for truth in case study research" (p.75). Bassey further suggests that creating an audit trail helps to make the research process trustworthy. Therefore I carefully dated, labelled and stored data using a systematic approach. A research journal entry illustrates my

awareness of the need to promote trustworthiness by keeping an audit trail:

"remember to use Basseys' (1999) case study book and notes in here when writing up the methodology section and remember to create an audit trail" (18th August 2011)

My response to how I equipped myself to be an ethical researcher was helped by questions I adopted to frame the ethical considerations. At each stage of the design of the case study, I asked myself the following questions. Firstly, was there potential for emotional harm to the participants as a consequence of my research? If there was a risk of this happening, how could I minimise the potential? A second consideration that I kept in mind was, how I could design the study in order to enhance the methodological rigour, trustworthiness and validity of the data? My awareness of ethical considerations means that I have reflected on this aspect of methodology continuously. This evidences my belief that ethical considerations are more than a regulatory process and, therefore, some of the issues relating to ethics have already been addressed in other sections of the thesis.

The following section discusses how consent, anonymity and confidentiality were considered.

Consent, anonymity and confidentiality

As previously outlined, the survey was sent to the 60 day care settings in one borough in England. The manager could choose whether to respond to the questionnaire that was sent out in the postal survey. If the questionnaire was returned, the participant's consent to use the data could be assumed. The next stage of the study involved semi-structured interviews with practitioners and parents; a letter of explanation (see Appendix 5) was given to them prior to interview to help

participants to give their informed consent. Consent from DJ's gatekeepers and his mother was sought to carry out observations of him in the setting. As Flewitt (2005) points out, there are two stages to gaining consent; first of all, what she describes as "provisional" (p.556) consent and secondly, ongoing consent. Flewitt urges us to remember that ongoing consent cannot be assumed and must be negotiated. The need to negotiate ongoing consent arose when mothers sent emails that contained useful data. I requested their consent to include this additional data because I believed that their consent to include data outside the interviews should not be assumed.

DJ was 20 months old when I started to observe him, and, because of his age, gaining informed consent from him was not possible. In the absence of a process for gaining informed consent, it is important to use other strategies to ensure that young children are not dissenting to their participation. Fargas-Malet *et al* (2010) suggest that children can demonstrate their displeasure by crying. However, I would not have wanted DJ to cry as a consequence of my presence in his setting. I would not advocate that a researcher should allow their actions to impact upon a child in a way that could result in distress. In order to minimise any potential distress, it is important for researchers to be aware that, as Alderson (2000) points out, the children are given the opportunity to become familiar with researchers. Therefore, I spent two periods of time visiting the setting in order to help the children become familiar with me.

The location of the case study is to be concealed in the writing of the thesis in order to protect anonymity. The absence of identifying codes on the questionnaires meant that the participant could remain anonymous. However, participants

who indicated that they were willing to participate in the next stage of data collection were able to indicate their wishes on the form. Pseudonyms were used to identify the participant at the start of the interview in order to help maintain anonymity. The mothers who participated chose their children's pseudonyms to help ensure anonymity. This decision was in line with Flewitt's (2005) suggestion that encouraging participants to select their pseudonyms can help to impart a sense of control to the participants. Asking the mums for a pseudonym was especially significant to DJ's parents. His mum said that she would like to think about his pseudonym. A few days later she emailed me the following: "we would like him to be referred to as DJ", thus implying that the choice of pseudonym was important and that it had been discussed and decided with other family members. Asking the mothers to choose pseudonyms helped me to explain the concept of anonymity.

Care was taken to ensure that electronic and hard copies of data were managed and stored with care in order to maintain confidentiality. Paper copies of emails had identifying data removed and the email was deleted from the computer. The digital recordings of the interviews with practitioners and parents were copied on to a memory stick and stored safely. Electronic transcripts were stored on a memory stick and the printed transcripts of the interviews were coded and stored in the data box along with the observation recording sheets.

I was conscious, at the design stage of the study, that I must not cause any harm to the relationship between parents and practitioners as a result of what they may say or reveal about each other. I was also aware that Kate's position, as a practitioner in the setting and DJ's mother, had potential to create tensions. Therefore, ensuring confidentiality about

the content of the interviews to the participants was a way of avoiding a conflict of interest that may have arisen as a consequence of what each other may have said. An exception to this consideration was my awareness that if something was said that I felt was an issue relating to safeguarding, and was a threat to the welfare of the child, then this is when confidentiality would have to have been breached and concerns would have been reported to the appropriate authorities. However, these were concerns that did not materialise.

Conclusion

This chapter has given a detailed account of the methodological choices considered and taken for this research. I have been very conscious of the need to explain this section because of the complexity of the case study structure. I have attempted to explain my reflexivity and positionality from the four autobiographical perspectives that have helped to shape my research. The next chapter discusses the approach taken to analysis of the data collected during this research.

Chapter 4: Analysis of the data

Introduction

This chapter discusses the approaches taken to the analysis of the data. Whilst analysing the data, I was conscious of Possick's (2009) view that reflexive analysis is a useful tool for qualitative data and to be mindful that this should not be confined to the methodology section. For example, my own awareness that occasions when food is made available times when food is available can be especially troublesome for people with dietary restrictions may well have meant that I was particularly attuned to look for DJ's actions and reactions during snack and mealtimes. Lahman (2008) distinguishes between reflection and reflexivity by offering the following: "If the act of reflecting is seen as occurring after an experience, then reflexivity occurs before, during and after an experience" (p.291). This distinction made sense to me and I was aware that I engaged with an on-going process of reflexivity at each stage of the analysis process. The reason for my need to be reflexive, links again to my awareness of the influences of my perspectives on the research process. My positionality may have led me to interpret the data to fit my subjectivity, which may have developed as a result of my perspective as a mother. However, this caution also needed to be balanced with Possick's view that previous emotional feelings can aid understanding, which can lead to insights that may not be possible without the personal experience of the researcher being brought to the research. Therefore, at the end of the year of observations, the experience of being with DJ and observing him gave me valuable insight. Firstly, I gained a sense of what it was like for him to be in the setting, and a flavour of how CHCs affected

him and his access to early childhood education. Secondly, I gained a sense of how the practitioners worked to include him in the setting. Finally, I gained a sense of the vital role that his mother played in promoting inclusion for DJ to the activities and his early childhood education.

This rest of this chapter explains the approach that was taken to organise and analyse the data. The period of data collection from November 2011 to March 2013 produced what Tyler (no date) described as "a mountain of data" (no page). Whilst collecting data, I was mindful of Tellis's (1997) advice about the importance of organising and documenting data as it was collected. This helped to ensure that the data was manageable and easily located.

The data included:

- 19 completed and returned questionnaires from practitioners who responded to the postal survey
- Transcripts of semi-structured interviews with practitioners and parents (see Tables 3.1 and 3.2)
- Email correspondence with DJ, Freddie and John's mums
- 2 questionnaires that were completed by parents in Setting 1
- Observations of DJ aged 20-32 months (see Table 3.3)

An explanation of the approaches used to analysis of the data is included in the following sections.

The survey

The questionnaire (see Appendix 3) was sent to 60 settings in order to collect quantitative and qualitative data. The response rate to the postal survey was 31.5% (19 of the 60 questionnaires were returned). Returned questionnaires were allocated a number from 1-19; the numbers were allocated according to the order they were received. Out of the returned questionnaires, 17 were completed; Settings 8 and 19

had returned the questions unanswered, although there were no apparent reasons for this.

The survey revealed valuable qualitative data that helped me to gain a picture of the incidence of children with CHCs in day care as well as help recruit practitioners to the next stage of the study. These data are included in the findings and it is indicated which setting the data came from.

In order to recruit children with asthma, allergy/anaphylaxis and eczema, the managers who had indicated that they were willing to participate further were contacted. It was hoped that knowledge about how practitioners created inclusive environments with all of the conditions would become participants. Diabetes and epilepsy are two conditions that are not as prevalent in young children as asthma, anaphylaxis/allergy and eczema (see Table 1.1). However, Setting 12 had two children with diabetes and Settings 16 and 17 each had a child with epilepsy, therefore they were high priorities to recruit to the next stage of the study. The managers had volunteered to participate to the next stage, and two were willing to approach parents to find out if they were prepared to participate and/or to allow their children to be participants. However, when the managers were contacted in February 2012, there had been changes of ownership and management in the three settings and the new managers were not willing to participate. This was a disappointment, and a salutary lesson in the importance of following up offers of research participation as soon as possible. As there was not an opportunity to recruit a parent or child with diabetes from the case, this was part of the justification for including John's family in the study.

The settings were approached in their allocated numerical order. Some settings did not respond to the contact and I was

unable to elicit the reasons why this was so. For some non-responders, it was partly to do with the ownership and managerial changes mentioned above that had affected many settings in the Borough. However, four settings (1, 4, 8 and 18) who had children with asthma, allergy/anaphylaxis and eczema, or a combination, were recruited to the next stage. Setting 1 was in an area of affluence and Setting 18 was in an area of high deprivation, therefore they were selected in order to recruit participants from diverse social and economic settings.

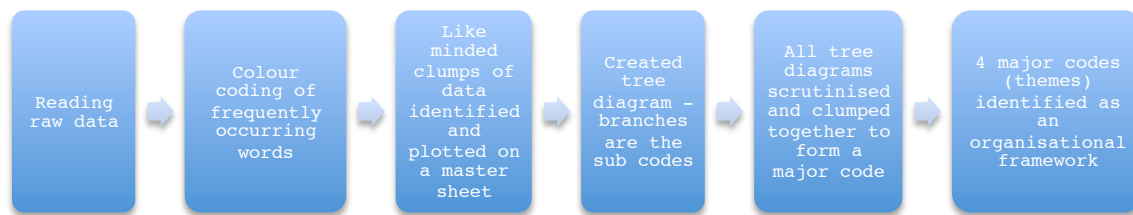
Analysis of the quantitative data

This section summarises the quantitative aspect of the survey. The quantitative data gathered from the survey was collated into a "group table" using Denscombe (2007, p.258) as a guide. The table is presented in the following chapter (see Table 5.1) because that is where the findings from the data in the group table will be discussed. Creating the table helped to identify the 13 settings who had indicated their willingness to be involved in the next stage of the study.

Analysis of qualitative data

In Figure 4.1, I have attempted to summarise the stages that I used to analyse the data, the following sections will then explain the reasons for this approach.

Figure 4.1: Process of analysis of the data - taken from Glesne and Peshkin (1992)



Analysis of data requires a researcher to reduce data in order to make it manageable, but at the same time keeping sufficient detail to give the reader confidence in the findings. The use of a computer software programme was considered in order to analyse the data, however I align myself with Corbin's (2008) claim that I have a non-technical mind and a preference for a non-technical approach. Therefore, the use of computer software was rejected and a manual approach was adopted. The first stage of analysis of data started with the transcript of the digital recordings of the semi-structured interviews. As I listened to the recordings, I kept the research question written down in front of me. I engaged closely with what was being said by the participants and, at the time, I reflected on how their responses would help to answer my question. After transcribing the interviews, hard copies were printed and the text was read line-by-line and commonly occurring words were identified and colour coded. The process of close engagement with the data reflected Charmaz's (2005) assertion that this can help the researcher to identify themes. The qualitative comments in the questionnaires were approached in a similar way, and, by using this approach, the data spoke for itself (St Pierre, 1997). For example, all of the practitioners who were interviewed mentioned parents on many occasions throughout the interviews. After the first highlighting of text, the highlighted blocks of text relating to comments about parents were written down on a master sheet. The name of the respondent and the page number of where the

data was located in the original transcript was included. This approach, as Denscombe (2007) suggests, was a useful way for me to gain answers to my research question "by looking closely at the empirical data that have been collected" (p.287). The sheets of data were then examined for common themes. For example, comments relating to parents appeared frequently in all of the data from practitioners. Therefore, the theme of the importance of working with parents emerged. The next stage of analysis was to create a tree diagram to illustrate the overall theme of working with parents.

The use of a tree diagram

Creating the tree diagrams helped me to reduce the mountain of data, which, as Tyler (no date) suggests, is a critical step in organising the main points of the data. Figure 4.2 is an example of the tree diagram summarising data from which the theme emerged of the practitioners' views of the parents' role in creating an inclusive environment for children with CHCs.

Figure 4.2: Example of a tree diagram



Another benefit of the tree diagram was that I was able to capture main points and some of these points were then used as headings for discussing the role of parents in helping practitioners to create an inclusive environment for children with CHCs.

After establishing a theme about the importance of practitioners working with parents, the data were then re-examined from the perspective of the parents. The data were examined to find out what parents had stated about the role of practitioners in caring for and meeting the needs of their children with CHCs. Colour codes were applied to parents' data and then I put "like-minded pieces together in data clumps" as Glesne and Peshkin (1992, p.133) suggest. However, using an inductive approach, the data revealed that a

successful aspect of working with parents was the ability of practitioners and parents to communicate with each other. Therefore, the data was re-examined from the theme of communication between practitioners and parents. As well as data about the importance of parent and practitioner communication, the data also revealed many examples of the importance of communication between practitioners in the setting. From this analysis, a third, correlated, clump of data emerged about the importance of practitioners communicating with other professionals. Therefore, a major code of communication was identified. Again, following Glesne and Peshkins' thinking, sub-codes were created and this helped to create "an organisational framework" (1992, p.133) for writing the story of my research. The codes created the themes or chapter headings. The sub-codes framework became the sub-headings. A diagram was created for the start of each main theme to give the reader a visual map of the contents of each theme.

Analysis of observations of DJ

The child tracking observation sheets (Bertram and Pascal, 2002) were used to collect data over a 12 month period from March 2012. However, the involvement level and learning experiences column were not relevant to this study, so they were not completed during the observations. The observations were analysed immediately after each period of observation by reading the words and examining them for a theme. This reflective process helped to inform the aim and the timings of the subsequent observations. For example, DJ's mum had highlighted that the symptoms of his CHCs were affected by the seasons. Therefore it was important that I observe him during the different seasons in order to capture any observable changes in the symptoms of his conditions. The dates and

times of the observations were tabulated after each period of observation (see Table 4.1). This enabled me to gain an overview of the contextual details of the observations, such as the season and the weather on the day of observation, as well as the main occurrences during the period of observation.

Table 4.1: Summary of the main points of observations of DJ

<p>Observation date and weather</p> <p>(6x3 hours of observations. 5 minutes every 20 minutes, different days and times throughout the day)</p>	<p>Key observations</p>
<p>2nd March</p>	<p>Familiarisation visit. Played happily outside Observed other children's food arriving at lunch time, other children did not look at each others' food</p>
<p>23rd March 2012. Cool spring day</p>	<p>Gained first impressions. DJ observes what is going on around him. Appears much happier when outdoors rather than indoors. Decided that adapting the Child Involvement Observation Sheet would be a useful observation tool</p>
<p>30th March. Sunny and warm early spring day</p>	<p>Noticed difference in food: 'The orange incident'</p>
<p>26th April. Sunny day</p>	<p>Listless following a 2 week absence and has been on steroids and antibiotics. 3.30 sitting and watching 3.50 still sitting – KP encourages him to play, picks him up and he snuggles in 4.50 animated and playing</p>
<p>24th May. Cool, dry day</p>	<p>Food difference: given melon and eats enthusiastically. Looks at the other children's snack, they have been given the same fruit</p>
<p>27th June. Warm and sunny</p>	<p>Wheezy. Happy and playful Goes to sand tray, KP calls over to his mum and checks he can play in</p>

Observation date and weather (6x3 hours of observations. 5 minutes every 20 minutes, different days and times throughout the day)	Key observations
	the sand "as long as he has cream on" several periods of sustained engagement throughout the afternoon
4 th November. Sunny autumn day with lots of leaves on the ground	Outdoor play in autumn sunshine, running around. Hamster in the room. Different food, but DJ does not look at other children's food. He eats with enjoyment
21 st March 2013. Cool and dry day	Recovering from an infection. Hot and clingy at times No obvious evidence of eczema

The notes made during observations were scrutinised and examined for key words that may indicate a theme that could be identified. As mentioned previously, during the first observation it became clear that meal and snack times were of importance to DJ. Therefore, future observations were planned with the aim of me being present in order to observe DJ at these times. At the end of each period of observation, key points were summarised and reflected upon in my research journal. Relevant comments from my research journal are included in the findings of the study. When the time came to write up the story of my research, I read back over the observation sheets and completed the summary of the main points of the observations in Table 4.1. The data from the observations were used to inform the main themes identified in the study.

This chapter has explained the approach that was taken to analysing the data. The useful advice from the literature

about managing the data and organising it carefully meant that I constantly engaged with data from the start of the data collection period. This helped the process of identifying themes. The next chapter gives an overview of the findings and reports on the quantitative aspect of the study.

Chapter 5: Overview of the findings from the data

Introduction

This chapter is where I start to report the findings from the data. The data collected in this study were rich and complex and many important findings were identified. The study used mixed methods to collect data to explore how practitioners create inclusive environments for children with chronic health conditions (CHCs). The first part of the findings from the quantitative data is presented in the following section.

Quantitative data: Findings reporting incidence and type of CHC

As the review of the literature in Chapter 2 showed, there is a paucity of research about the effect of CHCs on very young children's early education. Neither is it known how many children with CHCs there are in day care settings, nor which ones practitioners most commonly encounter. The questionnaire attempted to find out an indication of the numbers of children in settings, as well as which conditions affected them, in a Borough in England. The findings are presented in Table 5.1.

Table 5.1: Summary of data from survey - November 2011

Setting ID no	No of children in setting	Allergy	Asthma	Diabetes	Eczema	Epilepsy	No. of children with a chronic condition	Volunteered participation to the next stage
1	90	2 ¹	6 ²	0	3 ³	0	11/90 12%	Manager interview and possibly parent
2	65	2 ⁴	4	0	4 ⁵	0	10/65 15%	No
3	40	3	2	0	1	0	6/40 (15%)	N/A
4	84	0	5	0	4	0	9/84 (11%)	Practitioner not parent
5	21	1	1	0	3	0	5/21 (24%)	Contact details inc, not indicated level of participation
6	44	0	5	0	2	0	7/44 (16%)	No
7	46	1	3	0	3	0	7/46 (16%)	No
8	55	1	NG ⁶	NG	NG	NG	1/55 (5.5%)	Practitioner/parent/child
9	64	0	4	0	1	0	5/64 (8%)	Practitioner/parent/child
10	72	1	1	0	3	0	5/72 (7%)	No
11	40	1	1	0	1	0	3/40 (7.5%)	Parent/practitioner/child
12	16	0	1	2	0	0	3/16 (19%)	Parent/practitioner/child
13	54	10	0	0	5	0	15/54 (28%)	Practitioner
14	58	1	3	0	0	0	4/58 (7%)	No
15	54	1	0	0	2	0	3/54 (5.5%)	No
16	65	2	2	0	1	1	6/65 (9%)	Practitioner
17	100	1	6	0	2	2	11/100 (11%)	Parent/practitioner/child
18	85	3	5	0	6	0	14/85(16.5%)	Parent/practitioner/child
19	Not completed							Parent/practitioner/child

Setting ID no	No of children in setting	Allergy	Asthma	Diabetes	Eczema	Epilepsy	No. of children with a chronic condition	Volunteered participation to the next stage
Total	1053	30	43	2	41	3	114	
		3%	4%	0.18%	4%	0.28%	11%	

Notes

- 1 Eggs and dairy products
- 2 2 of this number also have eczema
- 3 2 of this number also have asthma
- 4 1 also has eczema
- 5 1 also has allergy
- 6 Not given

The quantitative data showed that out of 1053 children in the 19 settings who returned the questionnaire, 114 (11%) children were reported as having one or more CHCs. Further research is required to find out if the results of this study are representative of a wider national picture. However, in this case study, the figures help to deductively affirm that there are a significant number of children with CHCs in day care settings. The survey asked practitioners to report on the CHCs that were most common in their settings and the findings revealed that:

- The most common CHCs that affected children in settings at the time of the survey were asthma, allergy and eczema (some children had a combination of two or more of these conditions).
- The least common conditions were diabetes (0.18% reported in the study compared with an estimated 4% of children aged 0-4) and epilepsy (0.28% reported in the study compared with 0.4% of all children).

The numbers of children with CHCs in each of the settings that responded to the survey varied widely. The percentages ranged from as few as 5.5% in Setting 15 to 28% in Setting 13 (10 children with allergy and 5 with eczema out of the 58 in the setting). As previously mentioned in Table 1.2, it is estimated that 11% of children aged 6-18 months are affected by eczema. However, out of 1,053 children, 41 had eczema, which was only 4% of the overall figure. Therefore, it would appear that there are significantly fewer children in these day care settings with eczema than could be expected compared with the national incidence statistics. The reasons for this are speculative. One reason may be that parents of very young children with eczema do not choose to send children to day care settings; they may choose alternative arrangements for childcare. Another possibility is that mothers may choose not to work. This would concur with Daud *et al's* (1993) previously mentioned finding that there was a lower employment rate amongst mothers of children with eczema than the mothers of children without eczema.

There were low numbers of children with diabetes reported in the returned questionnaires. Only one setting had children with diabetes and I was unable to recruit them to the next stage of the study. Therefore, John's mum's offer to participate in the study was highly valued by me as it enabled me to explore the effect of the symptoms of diabetes on John's early education. The study produced very little data about children with epilepsy; this point is addressed later in this chapter.

Qualitative data: Structure of the research story

This section aims to explain how the findings have been organised to make telling the story of this thesis coherent

and clear. The qualitative data in this study were collected using a range of methods and the participants were practitioners, the parents of three children and DJ. The following table serves as a reminder of the children, the conditions and the contribution made by their parents.

Table 5.2: Summary of the children, their CHCs and contribution of their parents to the study

Child's name	Chronic health condition(s)	Parental contribution to the study
DJ – Setting 18 20-32 months old over the period of participation in the study	Allergy/anaphylaxis, asthma and eczema	4 Semi-structured interviews and emails over 12 months with DJ's mum
Freddie – Setting 8 35 months at the time of interview	Asthma and eczema	Semi-structured interview with Freddie's mum (20 th July 2012)
John - from outside the case Diagnosed with diabetes at the age of 15 months. 33 months at the time of interview	Diabetes	Semi-structured interview with John, his mum and dad (17 th May 2012)

My research journal (Musgrave, 2009-13) has been a valuable source of data since starting my doctorate research. There are numerous extracts that I have used to explain my analysis of data, especially relating to the observations of DJ. These extracts are presented in italics in the text.

As outlined in Chapter 1, throughout this thesis the word 'symptom' is used to describe "what the individual feels, subjective responses that are not directly observable or measurable by other people. An indication of a disease, noticed by the patient himself (sic)" (Oxford Concise Medical Dictionary, 2010). Because the children in this study are

under five, most of the symptoms documented in the data were reported by adults.

Nevertheless, the data suggested that the children were capable of reporting some symptoms themselves. This is discussed in Chapter 6.

The findings illuminate some of the complexities that are involved in creating an inclusive environment for children with CHCs.

In the next four chapters, the findings are presented under the following themes:

1. The effect of CHCs on children and families
2. The importance of communication
3. Considerations for inclusive practice
4. Responsibilities and qualities of practitioners

Each theme is discussed under a range of sub-themes and sub-headings. In order to set the scene for presenting the findings, Table 5.3 summarises these themes, the sub-themes and associated sub-headings.

Table 5.3: Overview of themes

Theme	Sub-theme	Sub-headings from sub-themes
1. The effects of CHCs on children and families (Chapter 6)	1.1 The effects of CHCs on children	1. Effects on children's and parents' sleep 2. Children making connections and showing an understanding of how to treat their conditions 3. Children noticing when they are given different food

Theme	Sub-theme	Sub-headings from sub-themes
		<p>4. The effects of medication and interventions</p> <p>5. Children's experiences of pain and discomfort</p> <p>6. Children being unwell and absence from early education</p>
	1.2 The effects of a CHC on the child's family	<p>1. Family routines and activities</p> <p>2. Parental concerns</p> <p>3. Parents and child care arrangements</p>
2. The importance of communication (Chapter 7)	<p>2.1 Communication between parents and practitioners</p> <p>2.2 Communication between practitioners</p> <p>2.3 Practitioners communicating with other professionals</p>	
3. Considerations for inclusive practice (Chapter 8)	<p>3.1 Adapting the environment in the setting</p> <p>3.2 Adapting the curriculum: activities</p> <p>3.3 Adapting the curriculum: outdoor play</p> <p>3.4 Creating safe places for food</p>	
4. Responsibilities and qualities of practitioners (Chapter 9)	<p>4.1 Qualifications, knowledge and training</p> <p>4.2 Administration of medication and medical interventions</p> <p>4.3 Responsibilities</p> <p>4.4 Qualities and dispositions of practitioners</p>	

At the start of each chapter there is a visual map of the contents of the findings in each section in order to signpost the content of what is reported under the umbrella of each theme.

Before moving on to reporting the findings, I would like to refer to the data in this study about children with epilepsy.

Epilepsy: a hidden condition?

An aim of this study was to find out about the effects of five CHCs on children's early education. However, there was a limited amount of data about children with epilepsy. The limited information reflects the small numbers of children in the general population who are likely to have been diagnosed with epilepsy, which is 1:279 or 0.4% of children. This is comparable with the small percentage of children reported as having epilepsy in the data, which is 0.28% (Table 5.1). The experiences of practitioners with children with epilepsy elicited three comments from the 19 respondents to the survey. The respondent from Setting 13 commented that his/her most memorable experience of caring for children with this CHC was when "a child had an epileptic fit on a practitioner's lap". The respondent in Setting 16 gave her response to the same question as "a child going into an epileptic fit and seeing her distressed". The respondent from Setting 17 made the point that "No amount of training prepares you for dealing with a fit... you need support!". These data are significant, especially if examined in conjunction with the data reported in Chapter 10 by Joan (Manager, Setting 1) about a child whose epileptic fits were becoming more frequent. As a consequence of the increasing number of fits, the child was facing the possibility of needing rectal medication to control the symptoms and Joan felt that she was unable to offer this care

to the child. These data may indicate that managing children with epilepsy is concerning for practitioners. Therefore, it may be that epilepsy is seen as a reason not to offer a place to children with this condition. This raises questions about how, if, and where, young children with epilepsy are given the opportunity to access early childhood education. The limited data about how practitioners create inclusive environments for children with epilepsy is a limitation of the study. Further research is required to identify reasons why it appears to be a hidden condition.

Conclusion

The quantitative data gathered in this survey have given an indication of the numbers of children with CHCs, but it is difficult to draw any robust conclusions from the data. Further investigation would be required to comment on possible reasons why there are significantly fewer children with CHCs in day care settings when compared with the numbers reported in the literature as summarised in Table 1.1. It is also noteworthy that there was a wide variation in the proportion of children with CHCs in the settings surveyed. Again, this requires further research to find out if some settings are more, or less, willing or able than others to create inclusive environments for children with CHCs

The qualitative data helped to provide the story behind the numbers. The following chapters report the issues that emerged from the data and help to tell the story about the effect that the symptoms of CHCs had on the families in this study, as well as reporting the impact on children's inclusion in education.

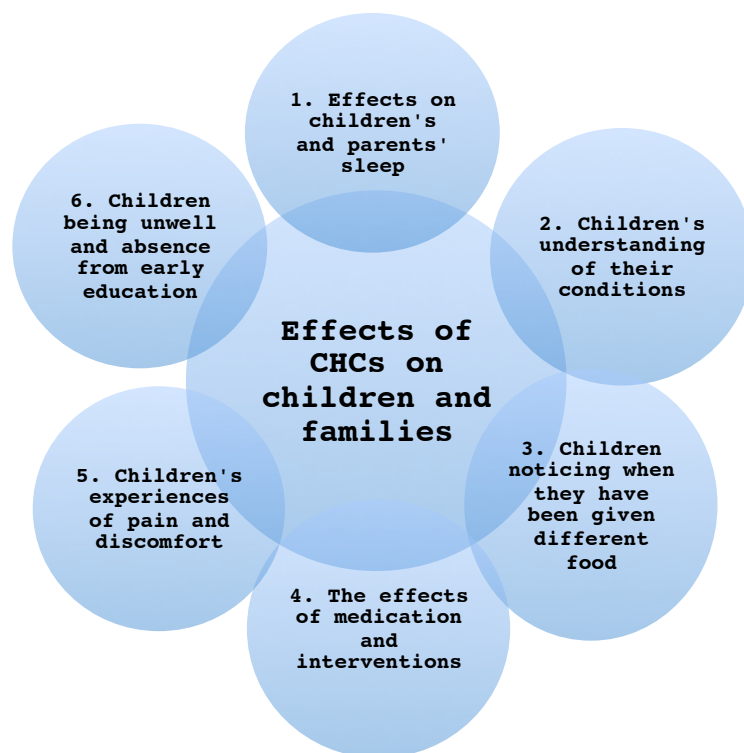
The following four chapters report the themes that emerged as considerations for inclusive practice for children with CHCs and their families.

Chapter 6: The effects of chronic health conditions on children and families

Introduction

This chapter examines the findings that illuminated how the symptoms of chronic health conditions (CHCs) were seen to have a profound impact upon the lives of children and families in this study. Figure 6.1 summarises the effects of CHCs on children and families reported in the data.

Figure 6.1: Visual map summarising the effects of CHCs on children



1. Effects of chronic health conditions on children and families

1.1 Effects on children's and parents' sleep

Freddie and DJ's mums reported the sleep difficulties experienced by their children. Over the year that I observed DJ (who had allergies, asthma and eczema) and throughout the interviews with his mum, the subject of sleep was a recurring topic of discussion. DJ's mum commented in an email: "DJ is still having interrupted sleep patterns, but some days he is managing to sleep for longer, up to six hours at a time. WOW! THAT IS VERY RARE!" (May 2012). She also said in an interview:

He slept through the night for two nights last week. We wrote it on the calendar because that's probably the first time that he's done that since Christmas. But it's changed because it's a lot warmer and, particularly during the night, because of humidity he is still scratching. He tends to have a really good scratch before he settles to sleep and then he can wake during the night as well – scratching. But also, because of the humid weather, it's affecting his asthma and since the weekend he's been having extra inhalers to help him with his breathing, he was up during the night over the last few nights coughing and you can actually hear the wheeze (June 2012).

Freddie's mum (Freddie had eczema and asthma), reported the similar difficulties that he experienced because of scratching at night. His sleep was disturbed so profoundly by his scratching that his mum consulted their general practitioner to get medical help. He was prescribed antihistamines (medication which can reduce the itching) but the side effect of the tablets meant that Freddie was sedated. This sedation had unsatisfactory results in that, as his mum reported, "in the mornings when he has had his sedatives he's not like himself, it's horrible, he's like a zombie, so we would rather have disturbed nights than have him like that".

The importance of undisturbed sleep for children has been discussed in Chapter 2, however, it is worth remembering here that on-going sleep disturbance has been shown to have considerable neurocognitive impairment (Brown and Reynolds 2006). Therefore, ensuring that children like Freddie and DJ have restful sleep in their setting may help to compensate for on-going sleep disturbance at night and may help to reduce cognitive impairment. Restful sleep will also contribute to the child's ability to participate in activities throughout the day. In turn, this will contribute to their wellbeing and happiness. This highlights the importance of practitioners and parents working together to create a sleep routine for children in the setting.

The data suggested that the practitioners in DJ's setting have achieved this aim, as illustrated by an observation of DJ's sleep routine:

Observation in the toddlers' room. 30th March, 1205-1210hrs: DJ has his nappy changed and cream applied to his body to soothe the eczema. He lies down on his back on the mattress, he is handed a comfort object, which is an item of clothing out of the washing basket from home. He lies and fingers the top of the vest. After 10 minutes of gently patting DJ's tummy, he falls asleep on his back. He sleeps quietly. The only movement is quiet breathing and movement of his chin and lower lip, as if he is sucking his dummy. The skin on his face and hands becomes pale and less angry-looking.

1405 hrs: DJ wakes up, stretches, looks around, gently pokes his ears and reaches for his comfort object. After a minute, he gets up and toddles over to the window... he starts scratching his wrists... he goes outside, he starts scratching his neck. Becky, DJ's key person follows him outside and says "let's put some cream on you DJ".

The observation suggested that the practitioners had created conditions that were conducive to DJ being able to achieve a sustained period of sleep that was peaceful and was not

interrupted by the need to scratch. The application of cream to reduce itching helped to remove physical discomfort or pain. The presence of an item of clothing from home as a comfort object (Winnicott, 1953) helped to relax DJ before settling down and he was emotionally able to relax. This suggests that planning, in combination with a familiar routine, was conducive to sleep. DJ's repeated disturbed sleep at night does not mean that his home routine and home environment is not conducive to sleep. It is possible that the therapeutic effect of the cream wears off after a period of time and this means that he is woken up by the need to scratch. This suggests that the sleep routine that DJ has during the day is particularly important to compensate for his disturbed sleep at night. The benefits of good quality sleep may mean that he is more able to concentrate and take part in activities, thus promoting his inclusion.

DJ's case illustrates the importance of practitioners finding ways in which to encourage children to maintain undisturbed sleep while in the setting. John's case provides evidence of a very different issue with regard to sleep related to his diabetes. In contrast to children with eczema or asthma, John's mum reported that if his blood sugar levels were high or low as a result of his diabetic control not being as good as they would like, his sleep pattern would be affected. He required much more sleep to the extent that John's mum said, "he will not wake up very easily". This point illustrates why it is important for practitioners to be aware of blood sugar levels in children who are receiving insulin for diabetes. It also highlights why it is important to monitor the length of sleep time that children with diabetes may take in a setting. While it is important for practitioners to accommodate children's need for sleep into a daily routine, this data illustrates that this becomes a particularly crucial issue for

children with CHCs and impacts upon issues of inclusion as well as health and wellbeing.

Sleep disturbance also affected the parents, not just their children. DJ's and Freddie's mothers described the profound effect of their child's sleep disturbance on their families. 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 (March 2012).

DJ's mum reported how her lack of sleep was increased when DJ became unwell. After a sleepless night in Accident and Emergency after DJ had an asthma attack, his mum had to get up throughout the following nights to administer inhalers to DJ. She said:

We had to keep giving him his inhaler during his sleep and then over the next five days it was stretched out to two hours, then four hours and gradually reducing the dose. It's been a long and exhausting weekend (November 2012).

Freddie's mum reported a similar experience about sleep disturbance:

My boyfriend works shifts so, if he was on afternoons, he would do every single night and then go to bed at 6 o'clock (am), when I got up, and that's the way we have had to work it so that we can both get some semblance of sleep... Me and my partner take turns (to go to bed), we are up in the night with him.

The examples of how children's CHCs can impact upon their sleep, as well as their parents sleep, are important for practitioners to understand because of the effect this can have on families. Such understanding can help practitioners to empathise with parents. This study revealed that

practitioners' ability to empathise was found to be an important quality for them to demonstrate, and helped to contribute to parents and practitioners working in partnership. These points are discussed further in Chapters 7, 8 and 9.

Having discussed the importance of sleep as a factor that impacted upon the child and parents, the next section reports the data that suggests that very young children have an understanding of how to treat their CHCs.

1.2 Children's understanding of their conditions

The data revealed examples that suggested that the children had developed an understanding of how to manage the symptoms of their CHCs. Taking note of what children can teach adults about managing their condition can give clues to how best to reduce the symptoms of these conditions. For example, the children seemed to make connections between the positive effect of medication and how it reduced the discomfort caused to them by symptoms of their CHCs. This was especially apparent in the children who had eczema. For instance, DJ's mum explained how he demonstrated this ability when he was 20 months old:

DJ has got his own little kit in his bedroom... he knows exactly what's what... if you ask him do you want your cream on? He'll say "yes" and he'll just go and get it. He has to be careful because the one cream is really large and heavy, but he's quite confident to just go and get it or he'll understand what we need him to do (June 2012).

Freddie's Mum recounted a similar experience, she said:

When he's scratching himself, he'll go and get his cream out of his bag 'cos we've got a bag with all his kit in, and he'll go and get it and tell us to put it on him. He was about two and a half. He brought me the suncream, I asked him why he brought me that and he was scratching and scratching and then I realised what he had done. I

said "you are the cleverest boy in the world!" - making a big thing of it.

The boys appear to have learnt that there is a connection between the application of cream and a reduction in itching they experience. One of the parents who completed the questionnaire in Setting 1 reported that her daughter, who was 28 months, "knows that she has two types of cream. One that mummy has to apply (the hydrocortisone) and the emollient, which she can help to rub in herself". The other parent who completed a questionnaire in Setting 1 reported that her son "is aware of what creams/medicines he needs... he will ask for cream if his skin is itching". Similarly, John's dad reported that at just eighteen months old, John's behaviour suggested that he made connections between the symptoms of his diabetes and action needed to treat his blood sugar. His dad reported:

He had gone in the kitchen and then he came back in with his pack with his meter in and then he gave it to me. He said 'check', and we checked it (John's blood sugar level reading) and it was low. He has done it a couple of times now, so he knows when it is low, but he doesn't know when it is high. So he is learning, now he knows what it feels like, he knows when it is low and that he needs something to eat.

This data could be interpreted as John demonstrating that he was not only recognising the symptoms of low blood sugar (even before his parents were aware of this), but was also understanding the action required to correct the situation. Episodes of low blood sugar levels (hypoglycaemia) can cause impaired cognitive development in children. Therefore, minimising or averting the number of hypoglycaemic episodes, or 'hypos', is important to avoid the risk of impaired cognitive development. John's actions have implications for practitioners in maintaining his health and promoting development. In the example above, John demonstrated his ability to recognise the symptoms of his CHC. His actions may

indicate his capability to be an expert in the management of his CHC. His ability to communicate how he felt may mean that some young children are capable of conveying important information about their CHCs. This point illustrates the importance of how practitioners may need to find ways to listen to the voices of children with CHCs in order to create an inclusive environment for them.

DJ's mum also suggested that DJ was able to not only understand, but also 'manage' his own symptoms of eczema. She reported:

DJ (aged 20 months) prefers long sleeved tops even when it's warm. He is aware... he has his T-shirt on and he tries to pull it down and he'll actually say something to us and he's desperately trying to pull it down (March, 2012).

This small example of DJ's thinking suggests that he has made a connection between the uncomfortable effects of the sun on his uncovered arms, or he may simply feel more comfortable with his arms covered. It is not possible to be definite about what he is thinking, but his behaviour does suggest that he has an awareness of his condition and how to treat it in order to minimise the effect of the symptoms. This example illustrates how children can acquire information about their bodies using, as Edwards and Titman (2010) suggest, a combination of cognitive development and direct experience. The data above suggest that these boys have learned how to make connections between cause and effect of aspects of their symptoms and how to minimise the symptoms. They have possibly made this connection by copying the actions of the adults who care for them. As Gopnik, Meltzoff and Kuhl (1999) state, people who care for children "naturally act in ways that promote and influence the changes in the children's representations and rules" (p.143). This suggests that

parents will have, perhaps deliberately, perhaps unwittingly, played a vital role in helping to teach children how to cope with their condition.

These examples of how very young children in this study have demonstrated an understanding of their conditions reflects the belief that young children are capable learners from birth. Gopnik *et al* (1999) also suggest that babies have the capability to make sophisticated interpretations of their lives. Such interpretations can play an active role in developing their thinking. The significance of how children with CHCs make connections and learn about managing their conditions is an important one for practitioners to be aware of, and highlights how children can teach the adults who care for them about managing their symptoms.

The next section reports further findings drawn from the observations of DJ that suggest he noticed differences in the food he was offered during meal times. The findings highlight tensions about the inclusion of children with allergies/anaphylaxis at mealtimes.

1.3 Children noticing when they have been given different food

Mealtimes are an important part of routines in settings and offer an opportunity for children to interact with each other and to develop social competencies. In turn, social competence learned at an early age is thought to aid the development of citizenship and inclusion in society (Baker, 2013). However, the provision of food for children who are unable to eat certain foods highlights some tensions for practitioners about inclusion at mealtimes. The data gathered from DJ was especially illuminating in this respect.

This section reports extracts from the observations of DJ made when he was aged 20–32 months. The findings suggest that he noticed when he was given food that was different to that of the other children. I have used reflections from my research journal as an analytical tool in order to extract meaning and interpretations from the data. The reflections are included in the text in italics. The first observation took place in the toddler room when DJ was 20 months old.

30th March 2012, 1205 hrs: lunch time. There are 12 children sitting around two tables, waiting for their bowl containing lunch. Chilli con carne is served in a variety of different coloured bowls. As the bowls are put in front of each child, DJ gazes at the contents of each bowl. A bowl covered in cling film with his name on it is unwrapped and put in front of him. "Here you go DJ, here's your dinner" (practitioner). The food is brown rather than the red coloured food in the other children's bowls. He gazes at his bowl and then looks again at the other bowls of food and his gaze follows the children's hands as they put spoons of the food into their mouths. A practitioner says "Come on DJ, eat your dinner". DJ shakes his head. The practitioner picked up his spoon and pretends to eat the food: "yum, yum, now your turn DJ". DJ starts to feed himself.

I have reflected on the use of the word 'gaze' in this observation and realise I selected it because DJ was not simply looking, but he was looking "steadily or intently, especially in thought" (Oxford English Dictionary). As well as gazing, DJ sat quietly, with his back erect and he fixed his gaze for a sustained period of time, watching intently and unsmilingly. The use of the word 'look', as opposed to gaze, demonstrates a less intensive scrutiny by DJ. DJ is an observer and his responses suggest he is beginning to understand that meal times are different for him (Research Journal entry 2nd April 2012)

1450 hrs: The 'orange incident' snack time – children are called to the table. A brightly coloured bowl containing orange quarters still in their skins is put in the middle of the table. The room smells of oranges and the spring sun is shining on the oranges and they are glistening. DJ is gazing at the oranges, as the children are invited to help themselves. DJ looks with interest at the children sucking on the oranges. DJ and another boy are given a bread stick by a practitioner "Oranges aren't for you DJ and Josh". DJ gazes

at the bread stick and then turns his gaze to a child eating a piece of orange, he repeats this action but looks at a different child each time.

1505 hrs: the children are still sitting at the table. DJ is given another breadstick. DJ points at the bowl, then his hand slowly goes towards the bowl, he puts his fingers on the edge of the bowl and a practitioner says "No DJ". He removes his hand but then repeats the action and sits for about 30 seconds with his hand on the bowl, his gaze alternates between looking at the breadstick and the orange segments. He takes small nibbles at the breadstick. He then slowly tries to move the bowl closer to him... a child is having his hands wiped and is told he can leave the table. DJ looks at the child who is toddling to the outdoor area. DJ makes a small sound, puts his half eaten breadstick on the table, and leaves the table, he runs to the door and returns to the outdoor play area.

The 'orange incident' haunts me. He is 20 months old and he is clearly noticing difference between the food that he is given and other children's food. What is he thinking? His level of 'stillness' is striking for such a young child. His attention from the events of 'the orange incident' was only taken away when he realised he could leave the table and go outdoors. He sits and gazes and is still and silent, clearly thinking deeply. The routines for meal times are lengthy and I am wondering if this makes mealtimes difficult for DJ? Perhaps a snack station would be better in order to avoid prolonged periods of time sitting at a table?

Charlotte (the manager) said in the interview that DJ had experienced an eczematous reaction to potato, when it came into contact with his face, his skin became inflamed. Charlotte and Sharon tried to wipe his face, but he pushed their hands away, an act they said was unlike him. He then refused to eat any more of his food. The practitioners thought that he had made a connection between the food and the pain/discomfort on his face (Research Journal entry 9th April 2012)

The next observation was made two weeks later when DJ was 21 months old.

27th April 2012, 1625: tea time – children are seated at tables. Plates of toast, bowls of grated cheese and bowls of apple slices are placed in the middle of the table. Children are helped by practitioners to serve their choices. There is no discussion about restrictions for any of the children. DJ looks at the food but does not gaze with intensity, he gives a quick look at the other children's food and settles down to eat. He eats two servings of grated cheese and a quarter of a

slice of buttered toast and drinks two cups of juice. He gives small, almost imperceptible nods of his head occasionally (DJ 21 months)

I am acutely aware that I have had an all-consuming interest in DJ and his responses to mealtimes. I was relieved that when he had tea the other day he ate with enthusiasm after he had checked that the other children were eating the same. Using observations has helped me, in a way that no other research method could have done, to see DJ's responses to food. Bertram and Pascal (2012) describe how observations help the observer to try and feel what it is like for a child in a setting, how the data can capture the moment, how the observer can use gut feelings and trust what is being observed. I feel as if I am a conduit that can pass on the information of DJ's responses to food in order to illustrate how he observes difference. I don't know what he is thinking, but my gut feeling is that he is either: perturbed, unhappy, or just wondering why his food is different. Or, is his response even more profound? Is he relieved that the food provided that he is offered is the same as the other children's food? Therefore, has he learned that the food is not going to cause him to have a reaction and is therefore safe for him so he can relax and enjoy eating? I would love to know what he is thinking. I would also like to make all his mealtimes the same as the one the other day, to make mealtimes more inclusive for him. (Research Journal entry 30th April 2012)

24th May 2012, 1055: morning snack – children are called to the table and seated as above. A bowl of melon is put in the middle and children are given a mug of milk each. The melon is served to the children, DJ looks at the other children's food and then looks back at his melon and starts to eat with enthusiasm. He repeatedly nods his head slightly as he is eating. 1115: DJ leaves the table

I observed another example of DJ having what I have come to describe as "an inclusive mealtime". It is a joy to see him looking, almost a glance, at the food, checking out that he has got the same food and then when he sees that he has, he eats with enthusiasm. I realise that the close observations of DJ make seeing what is going on under our noses so easy. However, the practitioners are not seeing his responses to food. There is clearly scope to find out if DJ's responses to food are common amongst children who require different food because of medical need. How do other settings manage the differences and what is good practice in managing meal times for children when there is a need for different food? (Research Journal entry 30th May 2012)

5th November 2012, 1035: morning snack – DJ is sitting at the table with 5 other children, fiddling with his comfort object and he is gazing at the other children as they are served from a bowl of sliced bananas in the centre of the table. Practitioner says “Snack time, DJ, do you want some banana?” he nods his head enthusiastically and says “Yes” emphatically and then eats with enthusiasm and drinks a cup of milk (DJ, 28 months)

Having read back over the other observations, what is really striking is how DJ’s body language is so different when he is waiting for food. I am recalling the observation from Monday and realise that it is significant to include even more detail of what I observed. I replayed the snack time over in my head and I remember that DJ was sitting very still, straight up in his chair. Again, he had the intense look, his gaze fixed on the food that was being offered. He appeared to relax visibly when he was offered banana. He started to nod his head and did small rocking movement with his legs. Was DJ expecting to be offered something different to the other children? Is this a source of anxiety to him? If I think about the still and alert demeanour he exhibits during the period he is waiting for food with his relaxed nodding and rocking after he is given the same food, I think it probably is a tense time for him (Research Journal entry 12th November 2012).

1155: start of lunch-time – children are seated around the table, waiting for lunch. They are making animal noises and pointing to parts of their bodies. DJ is joining in and smiling. The lunch trolley arrives. Children are clapping hands and banging the table. DJ is given his bowl of food that has been prepared separately. The other children have a tuna pasta dish, DJ’s lunch is pasta – it does not contain tuna – but looks similar to the other children’s. DJ gives a quick glance, but does not gaze intently.

1215: end of lunch-time – DJ is still eating using a methodical approach. He smiles as he eats. He has sauce around his mouth, but does not show signs of discomfort. He completes his lunch by eating a serving from the bowl of fruit containing apple slices and grapes, which is offered to all children.

As I am writing this part of my thesis, I am now reflecting again on DJ’s body language and wondering if his head nods are significant. He does frequent nods of his head when he is given the same food as the other children. Is his body language demonstrating that he is pleased that he has the same

food? He smiled during this observation when he has the same food. Does being given the same food make him feel the same as the other children and does this increase a sense of belonging? If so, this sense of being the same is important to DJ: even though he is so young, he is aware of difference about his food.

The next extract is when DJ is 32 months old and he has moved to the 2-3 year old children's room. The observation reveals further insight into DJ's striking ability to notice difference in relation to food.

21st March 2013, lunch-time – DJ is unwell, he had his temperature taken earlier in the morning because he felt hot. He is coughing occasionally. Several children have been unwell during the week. Children are seated waiting for lunch. DJ watches the practitioner handing out bowls of food to the other children. The other children have meatballs and pasta in a red coloured tomato sauce. DJ is given meatballs and pasta in a brown coloured gravy sauce.

DJ looks at other children's food. The other children do not look at each other's food! He starts to feed himself, it is hot and he stops. A student practitioner who is sitting beside DJ tries to feed him. She asks the practitioners if DJ's food is different, they respond briefly "Yes, he cannot eat tomatoes, so he has to have a different sauce". The student continues to make comments such as "Gravy with pasta is weird" she asks DJ "is that nice?" DJ nods and starts to eat his food independently.

The children are offered a serving of dessert. DJ continues to glance and occasionally gaze at their food. DJ is served a portion from the communal bowl. Other children do not look at each other's food. DJ nibbles at his pudding, but does not complete eating the portion.

DJ continued to be interested in the food that was served at snack and meal times. But, it has only just occurred to me at lunchtime during the last observation that this interest in food is not expressed by the other children. It was such a Eureka moment that I underlined the points several times on the observation sheet. There were eight children aged 2-3 years and although they were interested in the food they were given during the two meals I observed on the 21st March, they did not look at each other's food. Have to say that I could

have throttled the student when she drew attention to DJ's lunch. I was longing to explain to her the inappropriateness of her comments. However, DJ did not seem to pay attention to her, but he did respond when she asked him if his food was nice, which implies that he was listening. Not sure what this meant, perhaps he was simply hungry! (Research Journal 23rd March 2013)

I observed DJ for a year and during this time he consistently demonstrated behaviour that suggested that he noticed differences about his food. This reflects Nutbrown's (2011a) view that difference is of interest to children. It cannot be claimed that all children will notice difference in the consistent and striking way that DJ appears to have done, similar studies would be needed to investigate this further. However, an implication for practitioners is that giving DJ food that is different appears to affect his demeanour in a negative way. For example, closely observing DJ revealed his response to being given a breadstick instead of the oranges and the data suggested that this may have been a distressing event for him. The data suggest that he appeared to engage with mealtimes in a more positive way when all children were served the same food, possibly because he felt included in the social sharing experience of eating. These findings have implications for inclusive practice at mealtimes which are discussed further in Chapter 10. The use of observations will also be returned to in Chapter 10. The next section reports some of the effects on the children in the study of needing to have medication and interventions to control the symptoms of their CHCs.

1.4 The effects of medication and interventions

The data revealed that receiving medication is a frequent feature of children's lives if they have a CHC. The purpose of medications and other interventions are to reduce, or manage, the symptoms of CHCs and thus promote maximal

participation in activities. The two most frequent medications that were administered to children by practitioners in this study were cream, to suppress the symptoms of eczema, and inhalers, to reduce the symptoms of asthma. Freddie's mum highlighted the importance of administering cream to suppress the symptoms of eczema:

The most important thing for him is to keep his skin supple and moisturised, so that means the poor girls (practitioners) every hour, or every other hour, they are creaming him up.

As well as cream, DJ and Freddie required inhalers throughout the day.

John had to have a finger prick test up to six times a day. This involved a fine needle being pierced through his skin to obtain a sample of blood. The blood is applied to a test strip inserted into a piece of equipment for blood glucose monitoring. The blood sugar reading informs decisions about the adjustments that need to be made to the dose of insulin delivered by his pump to maintain his blood sugar at an acceptable level. Such procedures may have an impact on engagement with activities because children are interrupted in order to take medication. Clark (2003) reports the views of children aged four and above who described their resentment because of the disruptions caused by the interruptions required to have medication or take blood sugar level readings. The children in Clark's study were older than those in this study, however there is no reason to believe that younger children cannot also feel resentment as a result of the necessary interruptions. In turn, this interruption may disrupt "the finely balanced process of children's thought" (Nutbrown 2011a, p.28) and the possibility that this could have an effect on their cognitive processes is a consideration.

DJ's and Freddie's mums both estimated that preparation for bed could take up to an hour because both boys require creams and then bandages to be applied. As these are such time-consuming procedures for young children, there is always the possibility that they may cause them frustration.

Administering medicines and carrying out interventions such as blood sugar monitoring, required the children's cooperation, for example to wait whilst cream is applied or blood sugar readings are taken. If they need to have inhalers, they are required to cooperate and engage with the procedure so that the medicine in the inhaler is administered correctly and it reaches their lungs. However, the data revealed how DJ's key person appeared to have developed strategies to minimise the interruption to his activities caused by the need to apply cream. An illustration of how she did this is drawn from an observation of DJ when he was 24 months old:

27th June 2012 – 1345 – outdoor play area. DJ goes over to join his special friend who is playing intently with sand in the sand box. Practitioner notices and says "Hold on DJ" he stops and stands quietly, gazing at the practitioner. She calls over to DJ's mum, who is in another part of the outdoor area and asks if he can play in the sand. DJ's mum says "yes, as long as he has his cream on". The practitioner explains to DJ that she needs to put his cream on and to wait for her before touching the sand. She quickly locates his cream and joins DJ at the sandbox, where he has started to gently pat the sand. DJ puts his hand in the practitioner's hand, one at a time, patting the sand with his free hand. He remains engaged with playing alongside his friend as the practitioner applies cream rapidly, but gently.

1405 – DJ is still playing in the sandbox. He has had a sustained period of engagement with the sand. He has been scooping sand into a colander and making animated noises, not speaking words. He has been smiling. He has been taking handfuls of sand from the sandbox to another box repeatedly. After 20 minutes of engaging with the sand, he moves on to another activity in the outdoor play area.

As previously discussed, reducing the symptoms of CHCs is an important part of enabling a child to cope with their

environment and can increase inclusion in their early education. The example of how DJ's key person has developed her practice in order to minimise the interruption to DJ's play may appear insignificant. However, given that research on play indicates that this how children learn (Wood, 2013), it is evident that minimising interruptions caused by the administration of medicines, or the applications of cream, is an important aspect of good practice in order to include children in their early childhood education. However, even when children have medication administered to combat the symptoms of their CHC, they can experience pain and discomfort; this point is reported in the following section.

1.5 Children's experiences of pain and discomfort

Children's responses to pain and discomfort can affect their behaviour and it is important that practitioners understand the causes so that the reasons are not misinterpreted. There is limited literature available about, for example, the effect that the administration of ceaseless injections has on young children. Clark (2003) studied children aged 5-8 years of age and her findings report children's experiences of pain as a result of injections. However, she stressed that the pain children experience is not only physical, but also emotional pain. She claims that emotional pain is experienced because "injections do violence to the boundaries of self" (p.31). This could mean that children who experience pain are at greater risk of developing 'poor' emotional wellbeing (NICE, 2012, p.18). Furthermore, it highlights the importance of practitioners being aware that CHCs can cause pain and emphasises that they must be able to assess indications of their children experiencing pain and discomfort. The findings suggested that the children in this study experience pain and discomfort as a result of their CHCs. For example, there were many examples of the effect of triggers that provoked the

symptoms of eczema causing the child to itch to the extent that Freddie's mum said "He is always scratching and tearing his skin off". The discomfort caused by eczema is further illustrated by comments from DJ's mum:

He just flared up, he was bright red all over, he was really hot and there were white spots (June 2012).

His wrists are sorer than his joints, so they are sensitive at the moment because some of it is healing and some of it's still sore... sometimes he's sensitive and he'll roll down his sleeves because he doesn't want you to do that or sometimes he'll go "Ouch, ouch Mummy" (June 2012 - DJ aged 23 months).

Seeing a child in pain or suffering discomfort was also reported to be distressing for practitioners as well as parents. Practitioners were asked in the postal questionnaire, what their most memorable experience was of caring for a child with CHCs. For example, the respondent from Setting 2 offered that hearing "a 3 year old with severe eczema thanks us daily for putting their cream on: "you stopped me itching", was most memorable". Similarly, the respondent from Setting 18 suggested that "seeing the relief on a child's face when cream is applied" was his/her most memorable experience. Both of these examples make a connection between the positive effect that applying cream to the skin of children with eczema has and how practitioners can bring relief to children by ensuring they are applying cream effectively. Similarly, Charlotte (Setting 18) was visibly moved when she described the following incident that occurred after DJ's skin had come into contact with food that exacerbated a painful reaction to the skin around his mouth. She reported, "one of the staff brought DJ to the office and he wasn't crying and it was like he was used to that pain, he was in so much pain". DJ's reaction was not unusual, as Gill (2006) reminds us, "eczema is a painful condition and children

and adults with eczema often describe their condition as feeling as if the skin is on fire" (p.494). Charlotte's words clearly convey her awareness that DJ was in pain. McCaffery (1992) defines pain as "whatever a person says it is, existing wherever they say it does" (p.1). McCaffery's definition is difficult to apply to DJ because he did not say he is in pain. This may be partly because very young children are less likely to be able to convey such feelings in words because they may not have the level of vocabulary. Lack of ability to convey their feelings may be limited because children's understanding of illness and pain is age and stage dependent (Eiser, 1989). This can make assessments of pain in very young children difficult to quantify. Turning to the literature about children with life-limiting conditions who require palliative care to manage pain, there are assessment tools available (Hunt, 2005) to enable nurses to make a quantifiable assessment of their level of pain. However, it is not uncommon for paediatric nurses to rely on their knowledge of the child to assess their level of pain. In a similar way, it is important that practitioners are aware of the role they can play in reducing symptoms of CHCs that cause pain and discomfort as described in the data above. Part of their ability in recognising the signs and reducing the symptoms of CHCs will rely on the knowledge of the child but also the knowledge of the condition. For example, DJ's ethnic origin is Afro-Caribbean. This is significant because physiological differences in black skin, or skin of colour, can make the signs of eczema less obvious, however the level of pain experienced by the child can be significant (Kelly and Taylor, 2009). These points demonstrate another aspect of the complexity of managing the symptoms of DJ's eczema and highlight how his behaviour may not convey his level of pain.

As a result, his behaviour may be misinterpreted (NICE, 2007) and the need to relieve his pain could be overlooked.

Children with diabetes can have pain inflicted upon them as a consequence of having insulin injections and six finger-prick blood sugar tests each day. For example, John's mum described how his behaviour suggested that he "couldn't understand why Mummy was hurting him" when she was first injecting him with insulin after he was diagnosed. In addition, the symptoms of diabetes can make children feel unwell and can have an effect on behaviour. This point is illustrated by John's mum's description of his behaviour at the time he was diagnosed with diabetes at the age of 18 months:

He used to go round head butting the cupboards when he was first diagnosed, and smashing things, but he actually deals with it a lot better now.

The data that John's mum gave in this quote provokes the image of a bewildered little boy who is unable to understand why his life has changed and why he is being subjected to having eight needles (two for insulin injections and six blood sugar readings) stuck into his body by his mummy or daddy every day. He was probably wondering why his body felt different and, as Eiser (1989) suggests, children's level of understanding of being unwell is linked to children's age and stage of development. John at 18 months old, would have limited ability to understand the complexities of his situation, and his frustration and unhappiness may have been reflected in the behaviour his mum described above. John's response to the symptoms he was experiencing, because of diabetes, illustrate how children can react. The concern is that, even young children may have behaviour misinterpreted as unacceptable or even anti-social. This is another example of the importance of practitioners knowing how CHCs may impact on children so

that the reasons for children's behaviour are understood and appropriate action can be taken.

Although it is important for practitioners to be aware of pain in children, assessing how much pain very young children who are non-verbal, or lack the vocabulary to explain what they are experiencing, poses a particular challenge for practitioners. Brown (2007) discusses how pain in non-verbal children requires the adults to be exquisitely tuned in to identifying signs of pain. Brown's research is in the field of paediatric palliative care for children with life-limiting conditions, however there are correlations that can be used for children with CHCs. She suggests that parents of children who experience pain, and professionals who work with children who are non-verbal or have communication difficulties, describe "a 'language' of distress" (Brown, 2007, p.55) that children develop. She suggests that the distress caused by pain and/or discomfort can be a challenge for adults to recognise because "the interpretation of this distress is often implicit rather than explicit. In other words, distress is often noted as an impression rather than a conscious observation of behaviours" (p.55). Brown's assertions about how the adults in the lives of children who experience pain because of a health condition identify and respond to pain raises considerations for practitioners. Brown appears to suggest that adults form an impression that creates an intuitive understanding of interpreting the language of distress that children may develop in order to communicate their pain. For parents, it may be appropriate for them to respond intuitively, but for practitioners this may be problematic. For practitioners, this highlights the importance of finding out from parents the implicit information about their children's health. Practitioners can then interpret this information to make it explicit so that

all staff understand how to interpret individual children's language of distress.

These points highlight the need for practitioners to 'know' the child and understand how treatment works in order to reduce the signs and symptoms of conditions. By minimising children's pain and discomfort, practitioners are helping the child to feel 'well' and, in turn, children's feelings of wellbeing are likely increase. An increase in wellbeing can improve a child's level of involvement in activities as suggested by Laevers and Heylen (2003), thereby helping children to access and increase the quality of early childhood education.

The pain and discomfort caused to children because of their CHCs may predispose them to the risk of developing psychological difficulties (Edwards and Titman, 2010) when compared to children who do not have such conditions. However, these findings suggest that the children in this study exhibited behaviour that suggests they had become resilient to coping with the effects of pain caused by the symptoms of their CHCs. An example to illustrate this point is offered by the respondent from Setting 12 who wrote "The way there is no moaning when I sometimes have to give three injections throughout the day, whereas others moan over a scratch".

The background to this child is unknown but the data implies that the practitioner is impressed by the child's resilience to cope with the injections. Similarly, John's mum described how he cried the first few times that he had insulin injections, however she said, "he learned to stop crying, he learned he had to have them". John may have stopped crying for a number of reasons and it is only possible to speculate about them. One reason may have been that his parents became

more adept at giving the injections and therefore he experienced less pain. Or, as previously reported, he may have made a connection between feeling better and having his injections. Another consideration may be the child's temperament. For example, Freddie's mum talked about his response to the restrictions on his life because of the effects of asthma and eczema, she said, "He is very, very accepting".

As stated, the reasons why the children in this study were found to be resilient to the pain and inconvenience caused by the symptoms of CHCs are speculative. However, a common theme that emerged from the data was that all of the parents appeared to be equipped to help their children cope with the effects of their CHCs. David *et al* (2003) highlight the importance of children having parents who can "support the child in coping" (p.12) with the effects of living with a CHC. This is another example of how parents can have a positive effect on promoting their children's development and maximising their opportunity for learning (David *et al*, 2003). However, this point also has implications for practitioners because they too have a role in working with parents to help children to cope with the effects of CHCs. Therefore, working in partnership may help to enable inclusion of children in both their educational attainment and inclusion in society. The role of parents is discussed further in Chapter 10.

The next section looks at how CHCs can cause children to become unwell and how this can affect their inclusion in their education. It also highlights tensions that this situation can raise for practitioners and other children.

1.6 Children being unwell and absence from the setting

DJ experienced several episodes of being unwell and absence from the setting because of his CHCs. This finding concurs

with Marsac, Funk and Nelson's (2007) view that asthma causes a high rate of absenteeism in educational settings. The findings in this section are extracted from data collected during the observations of DJ and from interviews with his mum. The symptoms of DJ's asthma, eczema and allergies caused him to be absent from the setting because he had to attend medical consultations. His mum mentioned that:

We're going to the hospital next Thursday for his allergy tests. He's got one appointment at the hospital on Monday and another appointment on Wednesday (November 2012).

As previously mentioned, asthma, eczema and allergy/anaphylaxis are related conditions, however they are different conditions and require the services of staff with specialist knowledge. The management of DJ's CHCs required him to attend different hospital departments for appointments held on different days with different health care professionals. DJ had allergic reactions to a range of foods during the year I observed him. This resulted in him having to attend several hospital appointments for allergy tests in order to identify the allergenic foods. The effect on DJ and his mum is that they both have to take time away from the setting in order to attend hospital appointments. On one occasion, he required urgent medical attention and spent the night in Accident and Emergency receiving treatment for an asthma attack after which he missed two days of being in the setting.

The data revealed that DJ had several colds that triggered his asthma - bearing in mind that the common cold virus is the most frequent trigger of asthma symptoms. Each time he became unwell, he was treated with antibiotics and steroids. When he was particularly unwell, he would be absent from the setting. The common cold is a recurring cause of illness in day care settings, with children having up to ten infections over the

course of a year (Bush, Bossley, Fleming and Wilson, 2010). Preventing the spread of viruses that cause the common cold is a consideration for practitioners because this will contribute to creating an enabling environment for children with CHCs. For example, promoting effective hand washing procedures can help to minimise the spread of cold viruses in settings. Therefore, as previously mentioned, this may reduce the number of cold viruses that circulate and can trigger the symptoms of asthma, thus reducing the number of times children with asthma might become unwell and need to be absent from the setting and miss out on their early education.

During the year of data collection, I observed periods when DJ was unwell when attending the setting and this impacted on his involvement in activities. However, DJ being unwell had implications for practitioners and for other children in the setting. The extracts from my observations recount such an episode.

DJ is 32 months and he has returned from being absent from the setting because he had been too unwell to attend:

21st March 2013 – 0920. A cold day – dry and sunny. DJ has been unwell and several other children have also been unwell. DJ is in the 2-3 year old room. There is a range of activities in the room. The children are called to sit in a circle. DJ sits and rubs his eyes. He has “heavy eyes”. His mum comes into the room. DJ says “go home”. Mum says, “not yet DJ, later”. Mum leaves the room. DJ cries and has to be persuaded to stay in the room.

0940 – DJ has spent 10 minutes on his key person’s lap. He is still sitting quietly but he is still grizzling and occasionally coughing. KP picks him up and puts him over her shoulder. He closes his eyes. KP tries to cajole him and says “I am going to tickle you”. DJ keeps his eyes shut and tries not to smile, he then smiles briefly. KP says “You’re still not right are you”. KP says “Can we check DJ’s temperature?”.

The data suggests that DJ's key person has developed skills and qualities that help to effectively care for sick children. From my perspective, I realised that in my observation of DJ, I described him as having "heavy eyes", which is an informal description commonly used by nurses when assessing sick children. Brown (2007) describes children's physical manifestations of being ill and she notes that unwell children's eyes can lack sparkle and brightness. The description was based on noticing a difference in how DJ looked that morning compared to how his eyes usually looked. My ability to recognise difference was partly based on knowing DJ and having observed him for a year, thus reinforcing the place of observations by practitioners to assess children.

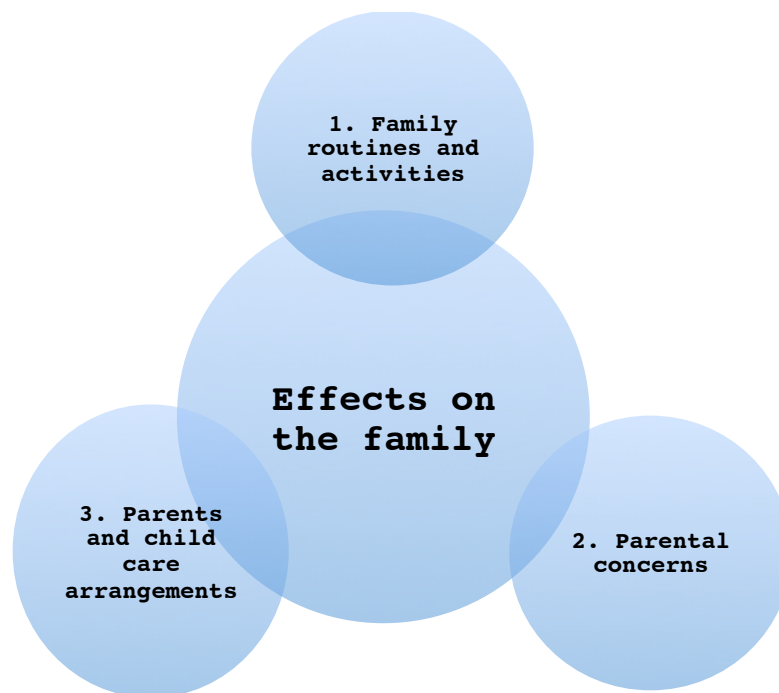
The observation above gives a snapshot of DJ's day at the setting where he rarely engaged with activities because he was feeling unwell. DJ's lack of engagement with the activities of the setting meant that he required more attention from his key person. However, this may have considerations for other children, to the extent that their access to the care of their key person may have been reduced, this point is discussed in Chapter 10.

So far this chapter has focussed on the effects of CHCs on the children in this study. Inevitably, the factors that affect children will impact upon their families and may lead to extra pressures on parents. For example, parents' sleep disturbance and consequent exhaustion is likely to impact on their wellbeing. However, sleep disturbance was not the only effect reported by parents in this study. Practitioners having an understanding of the effects of having a child with CHC on parents may be helpful in creating a positive relationship. The next section reports the data that illustrates the effects on the family of living with a child with CHCs.

2. Effects on the family of living with a child with chronic health condition(s)

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. Gaining an insight into the effects on the family caused by the symptoms of their children's CHCs may assist practitioners to appreciate the complexities such conditions present to families and in turn help to promote inclusion of families in settings. Obtaining an understanding of how parents have developed strategies can also help practitioners to develop inclusive approaches to adapting the EYFS. These findings include some practical considerations that practitioners may find useful when creating an inclusive environment. The findings also revealed some of the emotional effects on the parents in this study of having a child with one or more CHCs. Highlighting parents' emotional responses and anxieties can help practitioners to appreciate their role in reassuring parents about how they can care for, and include their children in settings. Figure 6.2 is a visual map of the points discussed in the next section.

Figure 6.2: Effects on the family



2.1 Family routines and activities

An over-arching theme reported by the parents in this study was the need to plan ahead in order to avoid situations that may provoke the symptoms of their children's condition. For example, Freddie's mum reported a lack of spontaneity because of the need to minimise the possibility of him coming into contact with triggers that may provoke the symptoms of CHCs.

She said:

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.

Freddie's mum also reported restrictions to everyday activities, such as swimming, and the need to limit exposure to the sun. Going on holidays was an area that was highlighted by Freddie's mum as needing extra planning:

We're going to Egypt at Christmas, we couldn't have gone in the summer because of his skin. Already now (June)

I'm talking to the doctors: shall we take antibiotics?
(in the event of his eczema becoming infected).

In a similar vein, DJ's mum talked about her holiday plans:

Even a simple trip to the beach needs thinking about. We haven't done that with DJ yet, we are planning to do so this summer... the sand really dries your skin, its quick as possible get it off and cream again. Just part of life, sand, swimming, sea, we will have a go, but we have to take extra precautions really.

John's mum also commented on the extra considerations that going on holidays created for her: "We are used to going on holidays and getting used to packing everything we need for John, it's part of life now".

Another effect on the families' routines that appeared in the data was how attending to the needs of children with CHCs can take up large amounts of their time. The effects of lengthy procedures and interruptions to activities have been discussed already, but clearly this impacted upon parents as well. For instance, Freddie's mum described how bathing, applying cream and bandages and administering medication could take an extra hour each evening to complete. DJ's mum described how shopping for food takes extra time because of the need to check labels for allergy inducing contents. In addition to these points, parents talked about the frequency of visits for medical consultations, which meant time away from work. The data from parents highlights implications for practitioners when they take on the role of caring for children in the absence of parents. In a similar way to parents, practitioners will have to consider the extra planning required for certain activities such as trips away from the setting. These points highlight the importance of practitioners promoting effective communication with parents. This is discussed further in Chapter 7.

2.2 Parental concerns

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 highlights 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, p.20). A baby like Freddie may be difficult to soothe and have impaired wellbeing because of the symptoms of eczema. A baby who is

“fussy” can impact on how the relationship develops with his key person; this point is discussed further in Chapter 10.

In addition, Freddie’s mum disclosed her anxieties about when he moves to school:

What if children won’t hold his hands? He’s got quite scabby hands and I’m scared that children aren’t going to play with him... when he goes to school they aren’t going to be used to him or his skin and that does frighten me, that he will be picked on and things like that.

The data from John’s mum convey a range of emotions that she had experienced, and was still experiencing, about John developing diabetes. Her experience reflects Bowes *et al*’s (2008) study, which reported the chronic sorrow that the parents of children with diabetes experience. John’s mum conveyed her sorrow about the effect of diabetes on John’s life; she talked about her feelings of guilt because she had taken him to visit relatives and at the time one of their children had chickenpox. A doctor at the hospital where John was treated when he was diagnosed suggested that contact with the chickenpox virus may have triggered John’s diabetes. John’s mum said that she often asked herself, if she had not gone ahead with the visit and John had not come in contact with the virus “would he have a more normal life than he does have? If I kept thinking what I was thinking, I probably would have gone mad.”

John’s mum also expressed guilt about not recognising that John had diabetes. Both parents felt this was something that they should have diagnosed because they were both trained paramedics:

Me and John’s dad just kicked ourselves in hospital. We kept going over and over – why didn’t we just do it (take a blood sugar level reading using work equipment), all the signs were there really. As a mother, I feel guilty, lots of guilt, that I didn’t do something sooner. That

is how I felt. It took me a long time to get past it. It gets easier all the time.

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.

Reading the data from the parents in this study conveys their depth of emotion and concern for their children. It is hardly surprising that such concern may manifest itself as a reluctance to be apart from their child. This appeared to have implications for decisions about childcare arrangements, a point that is examined in the next section.

2.3 Parents and childcare arrangements

The data suggested that for the parents in this study, their child's CHC raised additional anxieties about being separated from their children. Practitioners being aware of the psychological distress that parents may experience, because of concerns about their children's health, may mean that practitioners are better equipped to support parents.

Freddie's mum described her experience when she returned to work:

It was awful! I knew I wanted him to come here because my oldest son came here. But I didn't want him to do full time. Not just because he was poorly, but because he was so young. So my mum and my mother in law took him for a day each in a home environment. But I didn't really go back properly at first. I was going into the office, but I kept coming into nursery to check on him and that went on for a few months until he was nine or ten months old until I went back full time. I didn't want to but I had to.

Freddie's mum's words illustrate the dilemma that she faced trying to arrange childcare that she thought was right not only for Freddie, but for herself. These findings concur with

Page's (2011) findings that mothers face many dilemmas when going back to work. In the context of this study, the factor that heavily influenced Freddie's mum's choice of childcare was that her elder son had attended the same setting. She does not explicitly say that Freddie's health was an influence on her choice of childcare. However, what is evident in the data is the confusion that she experienced about her choice of childcare arrangements. Her reluctance about leaving Freddie was palpable. The importance of this is that her reluctance to leave Freddie may have been viewed by practitioners as over-protective behaviour as suggested by Mullins *et al* (2007). However, if practitioners were aware that her reluctance to leave him was because of her fears that Freddie's health status was, in her view, not stable, this would help practitioners to understand her behaviour and possibly allay her fears. For instance, he could have experienced an asthma attack, or a flare up of eczema, causing him pain and distress. An understanding of the vulnerabilities that parents may experience because of their child's CHC, can mean that practitioners are able to empathise with parents like Freddie's mum, and understand the dilemmas that they face.

The data suggested that DJ's mum resolved her childcare dilemma by working in close proximity to DJ because she worked in DJ's setting, but in a different room. She described how she worked in close proximity to both of her children; this was especially relevant as she reported that her eldest daughter also has the same conditions as DJ. She stated:

I would always make sure I was nearby. I've been quite lucky with my daughter, wherever I've worked she has either been with me or nearby so that I can treat her (March 2012).

DJ's mum implied that her childcare arrangements have come about because of luck, rather than her playing an active role in making it possible for her to work in the same building or nearby to her children's childcare. However, her geographical proximity meant that, when DJ had an unexpected reaction, she was able to attend to his needs. She reported:

He had an allergic reaction... luckily I was just across the hall in the other room, his face had swollen up on the one side and his lips had started to swell and then he was scratching his arms. So they called me and I gave him his anti-histamine and he had cold flannels over him... in the end I just stayed with him (June 2012).

This data demonstrated the instability of DJ's health, because an allergic reaction appeared without warning. However, DJ's mum was able to respond immediately and took on the responsibility for managing the incident. This probably had the effect of reducing her anxieties because she was able to respond immediately and stay with him until he recovered from the incident. However, this working arrangement is clearly not an option for the majority of parents of young children who have CHCs.

This section reports how the appointment of a different manager at John's setting meant that the childcare arrangements that were previously in place prior to her appointment became unsuitable for him and his parents. The data suggests that it is important for managers to show willingness and commitment to inclusion for children with CHCs. John was already at the setting when he was diagnosed with diabetes and John's parents had worked with the staff to teach them about John's care. John's mum explained how this situation changed and how this resulted in John not being included in his early education:

He was 13 months when he started at the nursery... he was there when he was diagnosed with diabetes. They were the first people to look after him. They had a new manager... I wasn't happy, I didn't feel comfortable with her looking after John for the whole day because of some of the things she was saying... she made me feel uncomfortable, (to John's Dad) you probably remember what she was like and what she was saying.

She said she couldn't understand what all the hassle was about, and it was easy to see when diabetic children were poorly. Then, on another day, they phoned up because he wasn't very well. The machine (insulin pump) wasn't working. When we went in the pump had become disconnected (John's Dad).

She had messed up, basically. He was having a hyper (high blood sugar). She said "He wasn't acting right. We can't get the machine to work". There was a bit of an atmosphere between her and another girl in the nursery who was very good and was quite clued up. The other girl said, "I told you that's how you do it". So after that I didn't take John back. I talked to my mum... my mum and dad started to help out more... Chris has days off in the week so they come over on the days that Chris is at work. And then, because John seemed to be getting quite bored, he was coming up to three, he needed other children to play with and be with, so he went to the childminder's on Mondays... John didn't like the childminder's. There were some naughty children there. He didn't like it. It is absolutely nerve racking leaving him... for somebody to look after him.

The findings suggest that John's mum was especially concerned about the manager's poor level of understanding and knowledge about John and his diabetes. The manager's comment where she stated that she "didn't know what all the hassle was about" imply that she has minimal understanding of the instability of DJ's health as a consequence of having diabetes. The manager's words also imply that in her view, John's parents are responding inappropriately and possibly in an over-protective way, as described by Mullins *et al* (2007). The consequent hyperglycaemic episode appeared to be a direct result of her lack of knowledge about the management of John's pump. This caused John to be unwell and unable to access his

early education. This example highlights the importance of practitioners demonstrating knowledge and understanding of CHCs. The findings about practitioners and training are reported in Chapter 9.

The examples from the parents in this small sample demonstrate some of the difficulties they have encountered whilst organising childcare. Whilst Freddie and DJ's parents had successful childcare arrangements, at the time of the data collection, this was not the case for John and his parents, whose current arrangements were temporary.

Conclusion

This chapter has examined some of the effects of CHCs on the children and families in this study and has raised a number of issues regarding inclusion. For me, the most powerful finding is the data that suggests that very young children have an understanding of how to 'manage' their conditions. Of almost equal power is the data from DJ that suggests that even the youngest children can notice difference in food in comparison with others. His behaviour could be interpreted to mean that having different food is an uncomfortable, and possibly a distressing experience for him. The findings have several implications for practitioners who are developing inclusive environments. For example, it is possible that the children's ability to understand their health, and notice difference is underestimated. However, my experience of observing DJ closely and getting to know him suggests that observations are a powerful tool for creating inclusive practice, this point is discussed in Chapter 10.

To conclude this chapter, 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 fact that symptoms of CHCs are complex and can affect children and families in many different ways.

Given that 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 an additional and sometimes substantial pressure, which may be under estimated. 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 whole family and in turn this can promote inclusion of the whole family, as well as the children with CHCs.

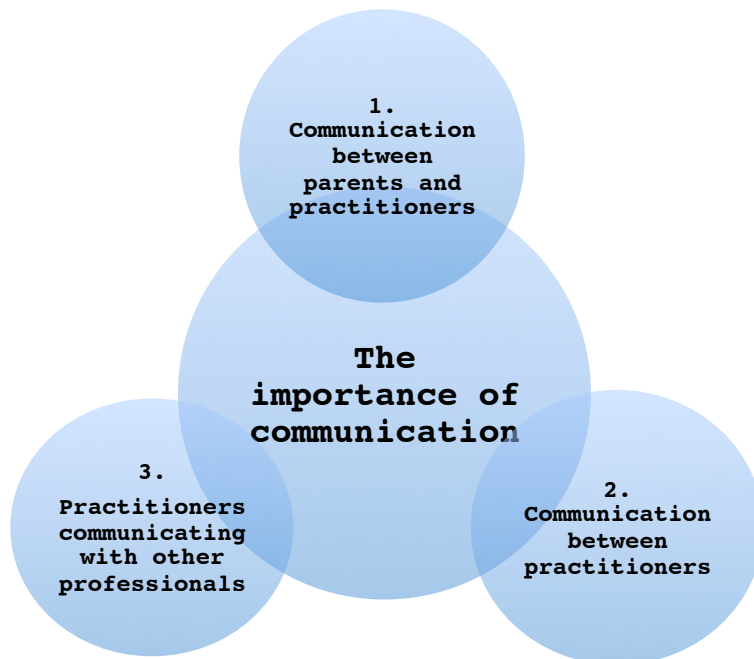
An important finding that has emerged from this study was how the parents became expert in managing their children's health. This expertise was a valuable resource for practitioners to help them plan inclusively. The data suggests that effective communication between parents and practitioners helped with the transmission of such information. The next chapter reports the findings from the theme of communication.

Chapter 7: The importance of communication

Introduction

This chapter reports the findings under the theme of communication. This theme reflects an aim of the EYFS in that it seeks to provide “partnership working between practitioners and with parents and/or carers” (p.2). The findings from this study suggested that a critical component of creating effective partnership is the ability to communicate. This included several facets of communication as summarised in Figure 7.1.

Figure 7.1: The importance of communication



1. Communication between parents and practitioners

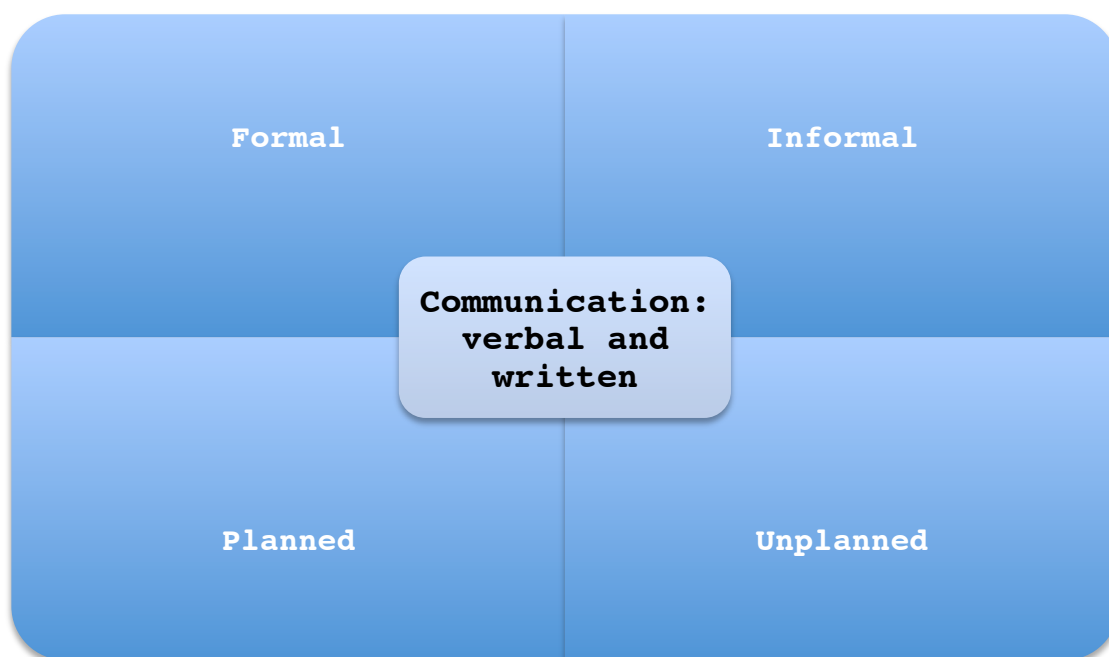
A theme that emerged from the parent and practitioner data, as well as the data from the survey, was the importance of parents communicating their knowledge about the effects of their child's condition to practitioners. The partnership approach to practitioners working with parents started at the first point of contact that parents made with a setting. All participating settings had a policy of holding an initial 'getting to know you' meeting with parents where health needs, as well as other relevant information, was gathered. This meeting informed the practitioners' decisions about whether they felt able to offer a place to the child; this point will be returned to below. The data also suggested that the ability of a setting to meet children's health needs was reliant on the parents' knowledge about their child's condition. Parents are seen, and act, as a conduit for information to practitioners that they had accrued about the management of their child's condition. 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 affects him in a way that is unique to him:

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.

The theme of parents being experts in their child's health is echoed by Mary's comment (Manager, Setting 14) "we are not the experts in this, the parents are". Similarly, Maria (Deputy Manager, Setting 8) stated that a key ingredient to creating

an inclusive environment is “having the right information from the parents from the start and working alongside the parents”. These practitioners’ comments suggest that they view parents as experts in their child’s health. The practitioners in this study appear to regard the role of parents, specifically their knowledge about their child, as the most crucial contribution to the setting’s ability to create an inclusive environment for children with CHCs. The communication between parents appeared to be an on-going process and there were several different modes of communication. Figure 7.2 summarises the modes of communication and these are discussed in the next section.

Figure 7.2: Modes of communication between parents and practitioners



The first mode of communication fell into what could be described as planned and unplanned modes of communication, which could be verbal or written. The planned communications included form filling such as medical records that captured

the medical history of children and included details of dietary restriction and medication requirements. Another mode of planned communication included the verbal discussions at the handover of the child at the start and end of the day.

Verbal communication took place on a daily basis at the beginning and end of the child's stay at the setting with verbal exchanges about the child from parent to practitioner. Joan (Setting 1) explained how the staff communicated on a daily basis with the parent of a child with diabetes who had attended the setting in order to adapt his diet: "We would talk to dad and he would say he needs extra pasta or rice today, because his sugar is low. Or we won't give him a pudding today because his blood sugar is a little bit high". In addition, Joan herself demonstrated her ability to think about how the weather could add another factor that could affect a child with diabetes:

We had to think, especially in this weather (very hot day, 28 degrees), if he was going outside to do exercise, he probably would need a biscuit or something... we would check with Dad, Dad would do his (blood sugar) levels before he left and he would say he is ok.

This exchange displays Joan's ability to communicate how she had thought to plan ahead to adapt the planning for this child. Her communication acted as a prompt to the child's dad to help her make the decisions that would enable Joan to include the child. This data also reveals Joan's knowledge about managing diabetes. Findings about training and knowledge are reported further in Chapter 9.

There were many examples of unplanned modes of communication, which included phone calls throughout the day. Joan (Setting 1) described how she would initiate a phone call 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.

Charlotte (Setting 18) revealed an example of unplanned communication with parents: "If the child refuses to have the inhaler, we have to contact the parent because we can't force the child to have it". This example revealed a difficult situation for practitioners. They would be aware of the need for the child to receive the inhaler in order to reduce the symptoms of asthma. The child's refusal could mean that he/she developed an asthma attack. Such an event would be detrimental to the child's health, and potentially fatal. Speaking to the parents may help the practitioner and parent to work out a strategy to persuade the child to take the inhaler. Thus, the parent would communicate some of their expertise to the practitioner and in turn the application of this expertise could help to avoid provocation of symptoms. Such an action could avoid the child needing to be absent from the setting and missing out on early education.

From Freddie's mum's perspective, communication was an important part of working with practitioners. She reported:

They will always ring me if his skin has gone bad in the day. They phone me and I will come and get him and I know they will do that. It makes me feel happy with them.

The practitioners' ability to communicate informally via telephone calls when necessary during the day appears to be important reassurance for Freddie's mum. In turn, this helps her to feel confident that Freddie is being looked after in the setting as she would look after him at home.

All of the practitioners described how they worked with parents in order to get the information they felt was

necessary to be able to meet the health needs and in turn, the education and care needs of children. Some practitioners assumed the responsibility of prompting parents to update them about changes to their child's medical status. This was evident in the policies that certain settings introduced. For example, Mary described the policy at her setting:

We update it every three months to make sure their medication hasn't changed, to make sure that if there is any change in their diet. The parents have to sign to say that here is no change in their diet or medication or anything like that. We normally send out a standard letter.

However, obtaining information from parents was not always a straightforward process and this blurring of responsibility created a tension for some, such as the manager in Setting 8. This next section reports the difficulties that staff encountered when trying to obtain information from a parent about her child who had been diagnosed with anaphylaxis to certain foods. Because the child was at risk of anaphylactic shock as a consequence of coming into contact with the allergenic food, he was prescribed an Epipen (an autoinjector containing adrenaline which can reverse the reaction and potentially prevent death). The child continued to attend the nursery, however, the mother had not supplied the practitioners with a list of the foods that must be avoided. Maria (Setting 8) described the situation as follows:

Mom was a bit half-soaked about things. It took a month to get a list out of her. He did bring his own packed lunch from home, but if he was here for tea, I needed to know what might start him off, we need to know these things.

This example illustrates how practitioners and children can be put in a vulnerable situation if they are not supplied with vital information that could affect children's health. The Managing Medicines in Schools and Early years Settings

Guidance (DfES/DofH, 2005) states that parents should supply information about the nature of the child's condition. The possible implications for this setting, if the child had experienced anaphylaxis during this period when the mother had not supplied the information about the lists of food he must avoid, are worrying. The Guidance states "if staff follow documented procedures, they *should* (italics added) be fully covered by their employer's public liability insurance should a parent make a complaint" (p.17). However, it is possible that the practitioners were not following documented procedures if the risk assessment and a health care plan did not contain details of the allergenic foods. The circumstances surrounding the reasons why the mother failed to respond to the requests to give a list of foods are not known. Neither is it known why practitioners took what could be viewed as a risk in continuing to keep him in the setting. Setting 8 is an independently owned business and relies on income from fees to be economically sustainable. The manager could have taken the decision to suspend the child from attending the setting until the information had been supplied. However, it is clear that denying the child access to the setting would have meant that he would have been excluded from his education. Also, denying the child access to the setting could have resulted in the mother becoming annoyed as a consequence of being inconvenienced, or she could have been offended by this action. The manager may have been concerned that the mother may have removed the child if she was offended, and this would have resulted in a loss of income. On the other hand, if the child had been exposed to an allergenic food and subsequently experienced an anaphylactic reaction, this could have been a cause for complaint by the parent(s). This incident also reflects the importance of parents being health advocates for their children, and part of

that role is not only knowing relevant information about their child but passing it on to practitioners. In this example, the parent failed to communicate effectively with the practitioners and provide the information that practitioners needed in order to keep the child healthy and safe, thus leaving him vulnerable to a potentially fatal anaphylactic reaction. This section has again highlighted the importance of communication with parents, as well as the difficulties that practitioners may experience if important information is not given to them. However, this study revealed that, as well as highlighting to importance of communication between practitioners and parents, communication between staff was also important. The next section turns to these findings.

2. Communication between practitioners and staff

The EYFS seeks to provide partnership working between practitioners. The importance of practitioners (and other staff) working in partnership by effectively communicating the needs of children with CHCs with each other was an important finding. A facet of communication that emerged from the data was the level of communication between practitioners about the management of children's health needs. Seven of the 19 respondents to the questionnaire emphasised the importance of communication between staff. For example, the respondent from Setting 9 wrote that there were visual displays in the setting to help communicate and educate staff about CHCs. It appeared that practitioners viewed it as important for all staff to be aware of the health needs of children; as Charlotte (Setting 18) stated: "It's not just us in the room, it's everybody in the nursery involved to make sure we do the best for DJ." Mary (Setting 4) conveyed a similar view: "It's the communication with parents and the team so that everybody is

aware of it really." Joan (Manager, Setting 1) also supported these views when she said:

It's all about communication and understanding the need for it and, again, communicating with each other, because it may be that the key person is away on holiday and it's making sure, whoever covers, that all the staff in the room know that child's needs. So it's not just the key person, the whole nursery needs to be aware.

These data highlighted practitioners' beliefs about the importance of intra-setting staff communication. However, the need for written and verbal communication about children's dietary needs was highlighted as being especially important. The subject of food in general is reported in more detail in Chapter 9, however, this section reports some of the findings about the need for good communication amongst staff in relation to children's food restrictions.

Not surprisingly, the need for communication amongst staff extended to the cook. For example, the respondent from Setting 15 spoke of the need to "make sure the cook knows all food allergies". This was mirrored by Joan (Setting 1) who described their formal and written procedures that are in place to communicate the dietary needs of children in her setting:

the chef then signs to say that this is the meal I've cooked, she then takes it to the key person. That key person will sign to say that I've received this.

Seven questionnaire respondents stated that formal, written policies and procedures were used in their settings to communicate children's health needs. For example, the manager in Setting 1 highlighted the role of planning sheets in order to communicate the dietary requirements. She reported:

They have got planning sheets that they do and there is a specific section if a child has any additional needs or allergies, how they would adapt it. So it's just to

remind staff to think, well actually oh, such and such is in today, we have got to remember if we have the dough out... Its' making sure that everyone has the information really.

Some of the written communication is designed not just to ensure the children's needs are met, but also to ensure that legal requirements have been fulfilled. To illustrate this point further, speaking of meeting the needs of a child with CHCs, the manager in Setting 4 reported:

We did the risk assessments and wrote to the insurance company... we make sure that the care plans and consent and care permissions all that sort of thing are up to date.

The usefulness of care plans is illustrated by a further comment from Maria, (Setting 8) who stated that "they (the children) have a care plan and we review it every twelve weeks because they are so little and things change so quickly".

Three of the respondents in the survey identified the use of health care plans as their main source of communicating children's health needs. In particular, creating an individualised health care plan for children with allergies is instrumental in minimising the risk to children of preventing anaphylaxis (Tang and Kang, 2008). Therefore, it was surprising that DJ's setting did not have a health care plan for him. According to Tang and Kang (2008), the contents of a health care plan should contain a summary of training and education required by practitioners to meet children's health needs. It should also contain information that educates staff about minimising the risk of an anaphylactic reaction. The information can help to raise awareness of the responses that are required to minimise the risk of fatality caused by contact with an allergenic substance. Reducing the risk and/or the severity of a reaction can help to minimise the effect on children's wellbeing and also reduce the amount of

time away from the setting that a reaction can cause, thus minimising exclusion from their education. Therefore, the attention given to updating the care plan is an example of good practice in keeping children safe as well as prompting practitioners to consider whether their practice is inclusive.

However, although it was clearly vital that practitioners within settings communicate effectively with each other, the data also revealed that communication with other professionals was an important aspect of inclusive practice. The next section presents the findings of communication with other professionals.

3. Communication with other professionals

The data revealed that the level of involvement with other professionals from the health service varied widely. The data from practitioners suggested that children with complex medical needs, rather than CHCs, were more likely to receive the services of health care professionals when in day care. Children with CHCs are less likely to receive the services of other professionals. The most likely reason for being in contact with other professionals is for training purposes. Several respondents described how the School Nurse or Health Visitor had been contacted for training or information. For example, training in the use of the Epipen was the most quoted training need identified by respondents in Settings 3,6,7 and 12.

Maria (Setting 14), the manager, requested that the parents asked the hospital to send copies of letters written after the child had attended for a consultation. This is an example of how the triad of parents, health care professionals and practitioners can communicate effectively in order to optimise the health of children with CHCs. It is noteworthy that Maria

holds the Early Years Professional Status (EYPS) qualification. The data relating to the qualifications of practitioners is discussed in more detail in Chapter 9. However, it is relevant to highlight the significance of Maria holding EYPS in this section. The EYPS qualification was part of the Labour Government's aim for the early years workforce to have graduate-led qualifications available for practitioners so that children under the age of five benefit from high levels of training (CWDC, 2008). According to Lumsden (2012), they occupy new professional space at the intersection between teaching, health and social work. Therefore, Maria's initiation in requesting copies of letters may be a manifestation of how EYPS practitioners lead on considering the health needs of children so that they can adapt the curriculum to accommodate these children. The request by Maria for letters to be sent to her to keep her informed about the outcome of children's medical consultations, demonstrates higher levels of thinking. This example may illustrate the importance of how practitioners engaging with higher-level qualifications, such as EYPS, can improve communication between health professionals and early years practitioners. The information in the letters received directly from health professionals may also help to reassure practitioners that they are getting the correct information. In turn, this may improve their confidence levels in how they approach adapting the environment to make it inclusive for children with CHCs. this may suggest that developing inclusive practice requires higher thinking skills in order to consider the ways to improve inclusion for children with CHCs.

This chapter has reported the data on the importance of communication as a vital component of inclusive practice. The managers emphasised the importance of communication with parents, however, it appeared from the data that the

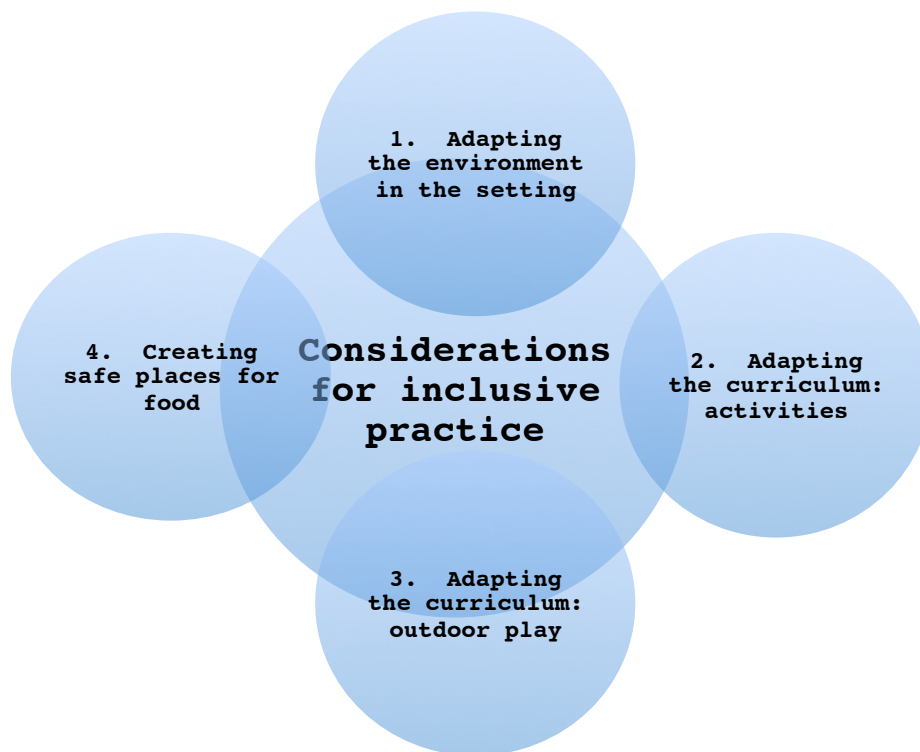
effectiveness of the communication with parents was as a result of the practitioners' abilities to ask the right questions. Their ability to do so may have come about because of their level of knowledge and understanding of the children's CHCs. The importance of communication between practitioners was also a notable finding. It appeared that on-going communication, especially verbal, was especially important when caring for children with anaphylaxis and allergy in order to minimise the risk of exposing a child to a substance to which they are allergic. The managers in this study played an important role in communicating with health professionals in order to access training. Clearly, the managers in this study play a vital role in developing effective communication to enable them to develop inclusive practice for children with CHCs. However, it is possible that the managers in this study underestimate how their higher levels of thinking contribute to developing the lines of communication. It is also possible that they do not recognise the vital role that their ability to communicate effectively has on the welfare and inclusion of these children. The next chapter reports the aspects of the EYFS that may require consideration by practitioners for children with CHCs.

Chapter 8: Considerations for inclusive practice

Introduction

The chapter reports specific ways in which the practitioners in this study adapted aspects of the EYFS to enhance inclusive practice. Figure 8.1 summarises some of the considerations that are reported here. The findings reported from this study so far have identified a number of factors regarding inclusion of young children with CHCs. Some of the findings suggest that full inclusion may be problematic. For example, the findings in Chapter 6 report the contentious area of inclusion at meal times for children with dietary restrictions. This chapter includes further findings about food. This is because the data revealed findings that suggest there are tensions for practitioners associated with the provision of food which have implications for inclusive practice. The next section starts by reporting some of the adaptations to the environment that practitioners considered for children.

Figure 8.1: Considerations for inclusive practice



1. Adapting the environment in the setting

The EYFS states that the premises must be suitable for children with disabilities. However, the findings from this study indicate that this is not just an issue for children with disabilities, because practitioners need to adapt the environments that they work in, to make it suitable for children with CHCs. Two of the adaptations that I observed related to the place of animals in settings and the use of detergents for cleaning. The EYFS highlights the value of children studying animals and as a consequence, two of the four settings had guinea pigs and hamsters for this purpose. However, animal hair can be a trigger for symptoms of asthma, allergy and/or eczema (Levy *et al* 2006). The recommendation

from the UK Clinical Guidelines for Atopic Eczema in Children (NICE, 2007) highlights the dilemma that removing pets from the children's environment raises. On the one hand, some children experience a profound response to the contact with animals. The response can be to the extent that health care professionals may recommend that animals should be removed permanently. On the other hand, the Guidelines recognise the important role that pets can play in children's lives, to the extent that "the psychological distress of pet removal may not be justified" (p.22). Becky, DJ's key person, demonstrated her awareness of the problem with having an animal with hair in the toddler room. She said:

We have a guinea pig and we have to be careful... if there's a problem for a child, I'd move the animal from my room and into another one so that it wouldn't aggravate him.

However, if all children are emotionally attached to the guinea pig, the removal may cause psychological distress for all of them, not just for children with atopic CHCs. This suggests that practitioners may need to consider if it is appropriate to introduce hairy animals as pets in settings. This would avoid the need to remove them if contact with their hair triggered atopic children's symptoms. The choice of animals to enhance children's learning raises a further consideration about choosing a breed that is unlikely to trigger symptoms in atopic children.

As well as animals, everyday chemicals were reported as being problematic. The EYFS highlights the need for providers to ensure that their premises comply with supplying equipment for hygiene requirements. However, the detergents used for laundry and hand washing may trigger a skin reaction. If the chemicals trigger the symptoms of eczema, this may reduce children's ability to engage with activities and can have

implications for inclusion. For example, three of the respondents in the survey mentioned that they had to supply soap and towels for children with eczema. This suggests that even simple everyday practices related to hand hygiene require adaptations. For example, Maria (Setting 8) described the level of care they took to ensure that Freddie's hand washing procedure was adapted to reduce the chance of his skin becoming aggravated. She said:

He uses an emollient to wash his hands because the soap was aggravating his hands. We've got paper towels which seem to be ok... we always make sure his fingers and the back of his hands are dry because that's one area they always forget.

Mary, Setting 14, reported another consideration about laundering bedding in the setting, she explained: "We launder our own clothes. If they need to have a certain washing powder, and not ours, mums take bedding home to wash".

This section has highlighted some of the considerations that need to be borne in mind when creating an inclusive environment. The effect on children of not implementing such adaptations may be disabling them from accessing activities and their education. The next section turns to considerations about adapting activities in order to ensure children with CHCs can access the curriculum.

2. Adapting the curriculum: activities

Activities that are planned in settings may be problematic for children with CHCs and this is a major issue for inclusion. The findings suggest that it may be difficult to adapt some activities to make them fully inclusive. For example, Maria, Setting 8, described how a sensory activity using shaving foam was problematic for Freddie because of his eczema. She demonstrated an innovative approach to adapting the activity:

We had shaving foam the other week and we had it on trays and we let the children, particularly the 2-3 year olds, explore it and my colleague was doing it with me and said "oh, what about Freddie's skin?" So I said "put some clingfilm over it and do it quite loosely so that he's not messing with the foam but he can poke it and press it and feel that it's soft and do what the other children are doing, not the wetness, but he can still explore it in that way.

Maria's example of how she adapted the shaving foam activity with the use of clingfilm with the intention of making the activity inclusive for Freddie raises questions of whether the activity is really inclusive. There was still a difference in the presentation of the activity. However, unlike DJ noticing the difference in food, according to Maria, Freddie "didn't bat an eyelid". This may suggest that Maria's approach to adapting the activity seemed to have included him, therefore her adaptation of the activity was inclusive for Freddie.

Maria highlighted a consideration for adapting a painting activity for Freddie:

Things like painting, making sure that if we are printing that he doesn't get too much paint. Sometimes, his hands are very, very sore and making sure that he doesn't get too much paint on them. Yes, we adapt it for him really. The one I can think of the most is the shaving foam.

In the example above, Maria described the caution they took to ensure that Freddie's skin did not come into contact with "too much" paint. However, how much is "too much" paint and how is that judgment made? This is possibly another example of where practitioners were required to use higher level thinking to make such a judgment. This point also raises questions about how practitioners exercise judgment to ensure that children do not come into contact with "too much paint". It also highlights the level of responsibility that practitioners carry in maintaining these children's physical safety and whether such responsibility raises anxieties for

practitioners? This concurs with Page and Elfer's (2013) finding that staffs' greatest anxiety is physical safety of children. It also raises the question of how that anxiety may be manifested. One suggestion by Rentzou (2013) is that practitioners can become reliant on nursery routines. This point is returned to in Chapter 10.

Turning to the children's perspective, if they are interrupted during a paint activity in order to minimise contact with paint, how does this make the child feel and does the interruption "disrupt the finely balanced process of children's thought" (Nutbrown, 2011a, p.28).

Another respondent showed similar innovation to Maria in the adaptation of activities for a child with eczema who was not able to play with sand because it triggered the symptoms. In this case, lentils were used as a medium for sensory play instead of sand. Moreover, water can be a trigger for children with eczema, and this was highlighted by 5 of the respondents in the survey. Practitioners demonstrated their understanding of the need to ensure that children had emollient applied to their skin prior to coming into contact with water. Another questionnaire respondent commented that a child with eczema wore gloves for messy and water play. Joan, Setting 1, reported how she thought ahead to think about the suitability of other activities that involve skin contact for children with eczema and allergies. She said, "We have got to remember if we have the dough out we have to be careful with the colouring. Or, if we are doing a cooking activity".

This section highlight some tensions that practitioners may face when attempting to strike a balance between including children in activities and at the same time minimising the impact of CHCs on children's activities. The findings suggest that practitioners demonstrate their awareness of the need to

consider the suitability of some sensory activities for children with CHCs. This section highlights that sensory play activities are especially problematic for children with eczema. The findings suggest that there are challenges to planning sensory activities that are fully inclusive for children with eczema. The findings also suggest that some of the actions taken to adapt activities are not entirely inclusive, for example Maria's description of the shaving foam activity.

The next section reports the considerations and adaptations to outdoor play arising out of the data.

3. Adapting the curriculum: outdoor play

Outdoor play required consideration for some children and especially those with asthma because asthma symptoms can be triggered as a result of physical exercise, such as running. For example, DJ's mum described how he had an asthma attack that was provoked by running outdoors:

He has to be careful when outdoors. Lately he only has to for a short walk or a quick run around and he's wheezy. His asthma attack started here and I had to take him to hospital in the end. So now, if he's out and he is going to be running, he has his inhaler before play-time and after play-time.

This is an illustration of how administering a puff of inhaler meant that DJ could safely run outdoors and he was able to partake in the activity. This action was mirrored by responses to the survey where practitioners explained how administering a puff of inhaler helped to reduce the chance of a child getting wheezy. For example, Joan (Setting 1) commented how she ensured that a child with asthma could have his participation in outdoor play maximised by remembering

that "if we have got football practice, he needs to have an inhaler beforehand".

Children with eczema also required additional considerations for outdoor play. Exposure to the sun needs to be managed for all children, and part of management is the application of suncream. However, suncream can be a trigger for eczematous skin. To reduce this risk, Joan (Setting 1) said that their policy is for parents bring their own sun cream. She added that "staff use separate gloves to put it on". Her comment demonstrates her awareness of the need to reduce the risk of another brand of suncream being spread on to the skin of a child with eczema because a practitioner used the same gloves for all suncream applications. Messy outdoor play also raised considerations for children with eczema. This is because sore and cracked skin is vulnerable to infection. In particular, practitioners demonstrated their concern about children playing with soil and with worms, which they felt could be a risk of infection. The consequences of a child getting infected eczema is described by one respondent to the survey in Setting 8 as her most memorable experience of caring for children with CHCs. She wrote: "One child had severe eczema and needed to be hospitalised as the eczema was infected". This highlights the need for practitioners to be acutely aware of the consequence of failing to consider the possible outcome of not adapting activities in ways that are appropriate for children with eczema.

Children with diabetes also required consideration about adaptations to include them in outdoor activities. If a child with diabetes expends more energy than anticipated, there is a risk of them going into hypoglycaemia, which is a medical emergency. Joan (Setting 1) described how she approached the

management of a child with diabetes in order to include him in outdoor play:

We had to think, if he was going outside to do exercise he would probably need a biscuit or something... he would have Ribena (high in carbohydrate) and we would take an extra (blood sugar) test just in case.

This comment highlights the additional planning that Joan was required to do in order to include this child in outdoor play.

This section highlights the high level of knowledge that practitioners possess about managing CHCs and how they apply this knowledge. The findings suggest that dilemmas arise about striking a balance between minimising children's contact or engagement with activities that may provoke symptoms and the need to keep children safe. This dilemma is especially evident in relation to providing food for children with CHCs and this is reported in the next section.

4. Creating safe places for food

The data revealed that the provision of food was a major cause of concern for parents as well as for practitioners. However food is considered in this section, rather than in the section about the effect on families because of the many considerations this subject raised for settings. The findings concurred with Pitchforth *et al's* (2011) study which reported the anxieties of parents about creating safe spaces for the provision of food. It appeared that managing the dietary needs of children with allergies was an area of tension for parents and practitioners and raised several considerations. For example, Joan, Setting 1, commented, when asked if she had encountered difficulties in creating an inclusive environment:

I think the main thing really is the meal times If a child has a severe allergy, we have a procedure... the

cook cooks their food separately... it cuts down on the risk.

As previously stated, although fatalities caused by anaphylactic reactions to foods are rare, they do occur (Muraro, Clark, Beyer, Borrego, Borres, Ledrup Carlsen, Carrer, Mazon, Rance, Valovitra, Wickman and Zanchetti, 2010). The most effective management for a child who has anaphylactic reactions to foods or substances is to avoid contact or ingestion of the food (Tang and Kang, 2007). In order to reduce the risk to children who have severe allergies to food, this study revealed that settings had procedures in place to prevent children from coming into contact with an allergy causing food. For example, DJ is allergic to fish, but fish is served in the setting to other children. Becky, DJ's key person described how they attempt to minimise the risk of cross-contamination:

All of his food is prepared separately. If it's fish, his will be prepared and then be wrapped up so there is no cross-contamination.

Preventing cross contamination of food was an issue that Joan was also acutely aware of. When asked about how the setting minimised the risks of children with allergies coming into contact with allergenic foods, she highlighted the lengths they went to prevent cross-contamination. She described the attention to clearing up food after meals were finished:

Making sure when you are clearing away that the child (with allergy) stays sitting down until everything is cleared away because it would be quite easy for them to think "oh, there is some food on the floor". They don't have food in the rooms, because children could quite easily take something up, things like bibs, tables, chair supports, making sure they don't come into contact with the food or the allergen.

The need to prevent a child coming into contact with an allergy causing food was also an issue for Sharon (Setting

18). She highlighted the dilemma of including children with food allergies at mealtimes as well as keeping them safe:

making sure he wasn't sitting right next to other children (when eating). You didn't want to ostracise him, but you didn't want him too close in case he touched something that could make him go into shock.

Sharon's comment indicated that children were physically distanced from food that may be allergenic to them in order to reduce the risk. This raises an issue about children being excluded from the social activity of eating. The data revealed the need to prevent cross contamination of food. Joan indicated that children under three were expected to remain seated until all food debris was removed to reduce the risk of contact with food that may have provoked a potentially fatal allergic reaction.

The data revealed practitioners' anxieties about keeping children safe and the need to be vigilant about the possibility of children coming into contact with food that is potentially harmful or even fatal. This point is illustrated by Sharon, (Setting 18), who described the anxiety of a practitioner who was previously employed at the setting. The practitioner was the mother to a child who attended the setting and the child was anaphylactic to some foods: "She was very nervous at children's birthday parties or Christmas parties with all the different foods around which made him quite jumpy".

This concurs with Pitchforth *et al's* (2011) findings where parents described how they became 'alert assistants' to help their children avoid dangerous food and create safe spaces for food. However, the data suggests that practitioners take on a similar role and become responsible for creating safe places for children with allergies to eat in the setting. It appears

that the attendant responsibility is a source of anxiety for practitioners. This is illustrated by Sharon's (Setting 18) comment, "it was more emotionally draining for staff because it was more of a life-threatening condition. We were always double-checking things". The emotional anxiety that practitioners experience as a result of the responsibility of caring for children with potentially life-threatening allergies will be discussed in later chapters and returned to in the concluding reflections.

In contrast to the policy in Setting 18, Setting 14 did not prepare food on the premises because food was sent in from home. Maria commented that she thought the catering arrangements made it easier for the practitioners to ensure that children with allergies were kept safe. She said:

It is easier for us because we don't have to stop and think, can they have that, or can't they have that? And phoning the parents every five minutes, so yes it does help.

The data suggested that Maria felt much more relaxed about the provision of food in her setting because the responsibility to provide 'safe' food did not entirely rest with her. This was in contrast to Sharon's experience described above. The next section turns to discussing the data from John's mum where she explains the difficulties associated with John being offered food, in particular carbohydrate, at celebrations. The implications for practitioners who care for children with diabetes are also discussed.

The data revealed considerations associated with adjusting food for children with diabetes. This was especially problematic when the normal routines were changed, for instance when John attended children's parties. Normally, John's mum read the carbohydrate content of food on the

wrapping. However, if they arrived at a party and food was laid out ready to be served, and the wrapping, with details of carbohydrate content were not available, she was unable to make the necessary calculations to adjust his insulin dosage. John's mum described the difficulty this created for her and John:

It is a nightmare, just a nightmare. We can't say to John, you can't have this, you can't have that, and the boxes are gone with all the carbohydrates written on them.

John's mum's words convey the complex considerations and planning ahead that is required to provide safe food for John; a situation which would be similar for all children with diabetes. If the required adaptations are not addressed, this could lead to children with diabetes becoming unwell. Therefore, the need for practitioners to understand how to manage the complexities are key to keeping children well, as well as enabling children to take part in social activities, such as celebrations. Despite the pressures on practitioners that creating safe places brings, this did not seem to deter practitioners from planning activities with food. An example is given by Joan (Setting 1), who described how she had liaised with the cook to find suitable ingredients for a child with an allergy to dairy products. She said:

My chef is brilliant, she has managed to find dairy-free chocolate so that he can be involved in making crispy cakes and there is nothing different for him.

This example illustrates how Joan and the chef managed to successfully and safely adapt an activity in a way that will not highlight difference.

Conclusion

This chapter has reported a wide range of considerations for practitioners implementing and adapting the EYFS for children with CHCs. The points highlight different approaches to activities to attempt to maximise inclusion for children with CHCs. However, it would appear that some approaches are not fully inclusive. It may be that planning around the needs of children with CHCs is a solution, as described by the respondent from Setting 9 who said: "We just plan around when the children are in the nursery". This approach could be a useful way forward. However, it must be borne in mind that children without CHCs may be disadvantaged. The data revealed the tensions that affect practitioners as they attempted to ensure the food served to children with CHCs was safe at the same time as including children in the social aspects of eating. The findings suggest that practitioners who develop inclusive practice take on extra responsibilities as well as demonstrating certain qualities. The next chapter reports these findings.

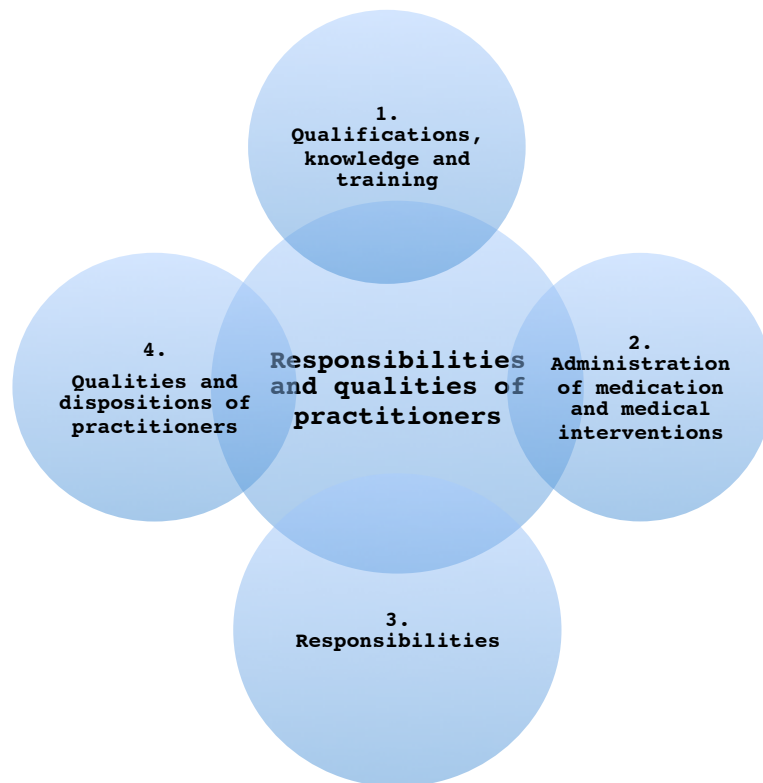
Chapter 9: Responsibilities and qualities of practitioners

Introduction

This chapter presents the data findings about the practitioners' responsibilities and qualities that were reported in this study. The data suggested that it is important for all staff, not just managers, to have a combination of personal qualities and knowledge to address the complexities associated with creating inclusive environments that emerged from the data. These findings reflect Hard and Jonsdottir's (2013) view that leadership in early childhood is defined by "a collaborative or team approach" (p.322). Leadership skills and qualities were especially important for practitioners to demonstrate when developing relationships and working in partnership with parents. The findings suggest that while many practitioners in this study were adapting practice and the environment in order to make it as inclusive as possible, others were not prepared to take on some aspects of care for children with CHCs. Such reluctance could be a barrier to inclusion.

Figure 9.1 is a visual map of the findings reported in this chapter. The chapter starts by reporting the findings about practitioners' views in this study regarding the need for them to have knowledge and training. This appeared to provide a foundation on which they could start to create an inclusive environment. This point is discussed in the following section.

Figure 9.1: Responsibilities and qualities of practitioners



1. Qualifications, knowledge and training

Some of the data reported in previous chapters illustrated a high level of knowledge and training about CHCs demonstrated by practitioners. This section reports the importance practitioners placed on having knowledge and training. The data revealed that the 19 respondents to the questionnaires were well qualified.

Table 9.1 summarises the qualifications of the respondents as reported by them in the survey.

Table 9.1: Qualifications of respondents to survey

Qualifications of respondents	Number achieved qualification
Early Years Professional Status	4
Bachelor of Arts: Early Childhood Studies	5
Graduates: other degrees	1 – psychology (and L3) 1 – not specified (and L3)
Foundation Degree in Early Years	5
Level 3	NNEB: 1 (and unspecified graduate) NVQ: 1 (and psychology degree) Unspecified Early Years qualification: 3

The table above shows that only 3 of the respondents held just a level 3 qualification and 16 respondents were qualified to level 5 and above. The EYFS sets the minimum qualification at level 3 for a manager. It is not possible to draw any generalisable findings from this very small-scale sample, but the level of qualifications reported by the respondents far exceeded the minimum requirement. The respondents' qualifications may indicate there is a connection between practitioners' awareness of the barriers that CHCs can present to children's ECEC and their ability to address such barriers. Also, it should be noted that the ability of practitioners to create an inclusive environment for children with CHCs is likely to improve the quality of the ECEC for such children. Therefore, this could be viewed as an example of how better quality ECEC can be provided if the workforce are qualified to higher levels (HMT, 2004; Nutbrown, 2012).

The data revealed that respondents reported that appropriate training about the medical requirements of CHCs enabled them

to understand the signs, symptoms and treatments. In turn, this enabled practitioners to manage the environment, as well as helping children to cope with their condition. For example, Charlotte (Setting 18) explained how training complemented the knowledge that parents could offer. She said "I think we could probably manage as long as we could get the training and the support from families".

The data revealed that respondents were either very confident or moderately confident about their level of knowledge and abilities to care for children with asthma, allergy/anaphylaxis and eczema. This is possibly a consequence of having children with these conditions in their settings. There was less confidence about levels of knowledge and their ability to care for children with diabetes and epilepsy. However, the practitioners who had children with these conditions were very confident about their knowledge and ability to care for them. This may suggest that some practitioners are reluctant to engage with training about diabetes and epilepsy, or it may be that training is difficult to access. It may be significant to have found out if the children with CHCs in this study had already been in the setting when they were diagnosed as it may be that practitioners were more able or willing to accommodate the health needs of a child who was already in the setting. In contrast, practitioners may feel that it is easier not to offer a place to a child with a pre-existing CHC.

The data suggested that managers used their knowledge of conditions to assess the likely needs of children when first contacted by parents. The practitioners in this study researched the needs of each child in order to help them make a decision about whether they felt equipped to offer a place to a child with CHCs. The data revealed that there was a lack

of consensus about which conditions practitioners felt they could manage. For example, Joan (Setting 1) was cautious about the type of medication she felt she would be able to administer to a child with epilepsy.

She commented:

It would depend on the condition and what they need. We had a little girl with us a long time ago, she needed rectal medication for her fits, that was something we were really unsure about. We were not trained for that and luckily enough we didn't have to do it. We got to the point where we said to mum, as the fits were getting worse, that this may be something that we wouldn't be able to do.

Joan's comments suggest that she was unhappy about taking on the administration of rectal medication. She makes the point that the staff had not been trained to carry out this procedure. However, this does not mean that training was unavailable. Joan goes on to say, "the child left us anyway, nothing to do with the nursery". The reasons why the child left are unknown. However, the child's mum is likely to have found it difficult to hear that the staff had expressed their concerns about the possibility of having to administer rectal medication to control the fits. This view suggests that Joan thinks there is a boundary to which she is prepared to go to accommodate the medication requirements of children with CHCs. In this example, it could be interpreted that the prospect of administering rectal medication was potentially a barrier to inclusion. However, this could also be interpreted as there being a boundary to her willingness to include such children in this setting.

This view was in contrast to Sharon at Setting 18, who commented that:

We have always tried to have every child that we can here in the setting. If we are not familiar with the allergy or condition, we will research ourselves, and get ourselves as much information as possible.

The data revealed that respondents used a wide range of sources to gain knowledge. Parents were the most frequently mentioned source of knowledge, but other sources included online searches of government websites, staff from other settings and health professionals. If managers identified a training need for staff there was mixed availability of training. Setting 18 had a significant number of children with complex medical needs (as distinct to CHCs). Consequently, they had a network of contacts with health care professionals that they could contact for training needs. Interestingly, Setting 1 was part of a large chain and had access to in-house training, but in a similar way to Setting 18, training needs were supplemented by the manager's network with health care professionals. Setting 14 was located on the site of a state maintained primary school and there was an arrangement whereby practitioners from the nursery were allowed to access the school's training. This highlighted a shortfall in the independent nursery sector because, as Mary (Setting 14) said, "the schools get training before we do in the private sector". The shortfall in training in the independent sector highlights a discrepancy with the state-maintained sector. The implications of a lack of training could mean that practitioners do not feel equipped to care for children with CHC and are consequently excluded from some settings.

The data revealed that the main reason given by practitioners for accessing training is because of the confidence they gained from knowing they are "doing the right thing" (Mary, Setting 14). The knowledge gained from training gave them

confidence to adapt activities, as well as to give medication and manage the symptoms of the condition. In turn, practitioners were able to take on the role of expert because they were able to think about the influence of factors such as the weather. For example, as described in the previous chapter, Joan demonstrated how she was able to prompt the dad of a child with diabetes to think ahead to the changes that needed to be made to accommodate the nutritional needs of the child, as well as assessing the effect of the hot weather. These adaptations would have helped the child to feel healthy and maximise participation in outdoor activity.

The data suggested that training and knowledge are vital for practitioners' abilities to create an inclusive environment. However, the data also indicated that obtaining training is not straightforward. It appears that there is a lack of clarity and consistency about how to access training. This is potentially a barrier to inclusion of children with CHCs. The next section discusses the issues for practitioners relating to administering medication and carrying out medical interventions.

2. Administration of medication and medical interventions

The effect of medications and interventions on children has been considered in Chapter 6. However, the findings suggest that there are several considerations for practitioners about administering medication and carrying out medical interventions. One consideration for them is the amount of time required to attend to administer medication. When asked how long practitioners estimated they needed to tend to the extra needs of children with CHCs, there was a wide range of responses. Some practitioners stated that the extra requirements took "a few minutes", whereas others estimated

15-30 minutes. The variation in the range of estimates is partly explained by Charlotte (Setting 18):

There is not a time that can be placed on this... every child's need is different and will depend on the condition and treatment required. For example, one child may require their inhaler once a day and another child may need it 3-4 times a day.

In addition to the administration of medicines there are other time considerations, for example, the time taken to communicate with parents and health professionals, as well as between practitioners. Administration of medicine in DJ's setting required two practitioners; the first practitioner, DJ's key person, initiated dispensing his medication and a colleague checked the administration details and both signed the appropriate form (Observation, March 2013). However, the extra time required for this purpose may not be accounted for, and is unlikely to be accounted for in the ratios of adults to children.

As well as being a time-consuming aspect of care, there may be other reasons why administering medication is an area of tension for practitioners. This point was illustrated by Joan's comments in the previous section where she expressed her reservations about administering rectal medication. It may be that she would not be prepared to administer rectal medication even if she was trained to do so. The reasons why the administration of rectal administration is not something that is acceptable to practitioners are speculative. But it is possible that administering rectal medication would be distasteful for some practitioners. Or it may be that practitioners have concerns about the intimate nature of the process. However, reservations about a particular mode of administration may mean that practitioners decide that some children's health needs cannot be accommodated in the setting.

Another consideration is that administering medication is a significant responsibility for practitioners. It also raises the important point that the Managing Medicines in Schools and Early Years Settings Guidance (DfES/DofH, 2005) outlines the responsibilities associated with caring for and administering medicines to children with CHCs. The Guidance advises that arrangements about who should administer medicines within a setting are individual to each setting. Such arrangements can be "either on a voluntary basis, or as part of a contract of employment" (p.17). If practitioners do administer medication, they need to have adequate training. However, as access to training can be problematic, this situation may mean that settings may be able to avoid taking responsibility for administering medication. This situation could mean that children with CHCs who require medication are not offered a place in a setting. Or it may be that, if a child develops a CHC and requires medication, lack of training and lack of a suitable person who is willing to carry out certain procedures may mean that a child is unable to continue attending their setting. For some practitioners they may feel that the level of responsibility associated with this aspect of care for children with CHCs is beyond the limits of their role. The next section examines other areas of responsibility for practitioners when creating inclusive environments for such children.

3. Responsibilities

The previous section discussed the responsibilities associated with administering medication for children with CHCs. This section reports the findings that revealed other areas of responsibility for staff when planning for the needs of children with CHCs. The data implies that there may be tensions for the key person being able to meet the

responsibilities to other children in their group because of the needs of children with CHCs.

The data indicated that the managers played a key role in taking responsibility for children's health needs, especially when there was a need for communication with parents.

However, the data suggested that it was important for all staff (including the cook) to share the responsibility of keeping children safe. In Settings 8 and 18 there appeared to be an overlap between managers' roles and the role of the key person and it appeared there was a shared approach to sharing the care and education of children with CHCs. This is illustrated by Charlotte's (Setting 18) comment where she explained how the practitioners shared the responsibilities of caring for children with CHCs by saying "we all do it equally", thus, demonstrating a leadership style that is defined by its collaborative and team approach (Hard and Jonasdottir, 2013).

The managers who were interviewed commented on how they disseminated the contents of conversations with parents to the child's key person. This implies that the key person appeared to have a limited role in communications with parents.

However, Mary (Setting 14) said that she would "be happy to allow the key person to talk to staff as long as she knows what is being said in the conversation". The fact that managers appear to take over the role of communication with parents may be because they wish to ensure they are aware of the contents of conversations to ensure that procedures were followed and documented correctly. For example, Mary, in Setting 14, described how she recorded agreed actions with parents, "so that we are covered". Maria's comment highlights the responsibility that can accompany some aspects of managing the medical needs of children with CHCs.

Another reason that managers may have taken on responsibilities for communicating with parents from the key person is because the key person would have been caring for other children in his/her group. If a key person has to repeatedly leave her key children to talk with parents, this may present him/her with a dilemma about how to meet the needs of all his/her key children. This could be another reason to explain why managers may have taken responsibility for the communication with parents. This point is returned to in Chapter 10. Despite the lack of clarity about the extent of the key person's role about some aspects of the care of children with CHCs, Becky, DJ's key person, indicated that she had an important role in meeting the health needs of children with CHCs. For example, she felt that part of her role in creating an inclusive environment was to "do as many observations as possible". She stated that the observations helped her to identify what provoked DJ's symptoms and the findings informed planning for DJ's education. However, there may be room for Becky to exploit the use of observations as a useful tool to develop inclusive practice even further, this is a point which is discussed further in Chapter 10.

The data appears to suggest that it is difficult to have clear-cut areas of responsibility and boundaries of responsibility are blurred. The data suggested that it was not always clear whether parents or practitioners were responsible for some aspects of the care of children with CHCs. The level of responsibilities shouldered by practitioners and especially managers appeared to be linked to their personal qualities; this point is discussed in the next section.

4. Qualities and dispositions of practitioners

This section reports some of the personal qualities that the practitioners in this study demonstrated in order to address the complex needs of children with CHCs and their parents. The qualities these practitioners demonstrated reflected those associated with effective leadership in early childhood education and care (Aubrey, 2007). Their leadership qualities resonated with what Jonsdottir (2009, in Hard and Jonasdottir, 2013) described as a "discourse of niceness" (p.319). The 'niceness' meant that the practitioners demonstrated a caring and positive approach to nurturing not just the children, but the parents too. Data from practitioners revealed the qualities they thought were important for them to possess in order to create an inclusive environment.

Maria (Setting 14) summarised some of the qualities she thought were important:

Open-mindedness and a willingness to learn from others... working with other professionals... we want their advice, we want to hear what they have got to say. I have been in settings before where they don't listen and don't want to know, but that doesn't help the child, we are here to here to help the child.

Charlotte (Setting 18) also demonstrated her willingness to take on children with CHCs as a quality that helped her staff. This was apparent when she reported "I think we could manage, we'd give it a go anyway. We'd definitely give it a go at including them – yes."

Other important qualities were reported by Charlotte and Sharon (Setting 18) as "being proactive... positive... open-minded... flexible. Welcoming. Showing respect". Charlotte and Sharon both felt that empathy with parents was an important quality for them to demonstrate. Charlotte said, "we have empathy that their child has these conditions and

they (the parents) are confident that we are able to address and meet their individual needs". Page and Elfer (2013) found that the ability of practitioners to show empathy arose from the individual resources of the practitioners in their study. Similarly, the practitioners in this study displayed qualities such as warmth and the ability to empathise with parents. The personal qualities demonstrated by the practitioners promoted a feeling of confidence in parents. For example, Freddie's mum's commented that she had confidence in the staff because she had the feeling that "they do take care of him the way I do". The parents appeared to recognise such qualities in practitioners and this appeared to help them to decide whether the setting was going to be able to care for their child and their health needs. However, Freddie's mum was unable to articulate exactly why she chose Freddie's setting. She offered the following comment: "I went to look at a few, you get a feeling. Not that I didn't trust the other people, but this just felt better for me". This comment suggests that the practitioners conveyed feelings that they could be trusted with looking after Freddie. This need for trust was reflected in Charlotte's comment. She said, "they need to trust us... it's a big step for them to bring them here, especially when they are babies". This section highlights the positive personal qualities that were evident in the practitioners in this study. The data suggests they make a personal investment in striving to create inclusive environments.

Conclusion

This chapter has reported the findings about the depth of knowledge the practitioners demonstrated about CHCs. The findings highlight that training and knowledge are important for practitioners to be able to develop inclusive practice. However, there is a lack of consistency about training that is

available for staff who are caring for children with CHCs. The findings revealed the willingness of many practitioners to take on a range of responsibilities, including administering medication. All considered, the data suggests that many practitioners caring for young children with CHCs were demonstrating key characteristics that are associated with leadership (Aubrey, 2007). Furthermore, the findings suggest that not only did all staff demonstrate effective leadership qualities, but also they demonstrated a collaborative approach. The importance of practitioners possessing certain qualities to use to create an inclusive environment can be illustrated by the data as reported by John's parents, as documented in Chapter 7. In this case, the manager's lack of effective leadership appears to have been the main reason for John being removed from his setting. John's mum reflected on their experience and, when asked to summarise what she would have wanted from practitioners to be able to care for John, she said:

I would want them to be thorough, to fully understand. Firstly, John's illness and if they don't understand, I want them to be able to talk to me to call me up and say I don't understand and ask me rather than pretending they do understand. So, honesty, I guess to be loyal and loyal to John as well, not just me. And to be warm and loving towards John especially if he is really high or his sugars are low, John wants cuddles and lots of loves. So that's it really, I want them to be honest and say if they understand it or don't understand it because that is going to have an effect on John if they don't understand it, which is what happened.

John's mum's words highlight the importance she attached to John receiving love from practitioners. This reflects Page's (2011) findings that concluded that the mothers in her study felt that love was an essential factor for their children. For children with CHCs, love from practitioners may be even

more important in order to mitigate the effects of symptoms on their lives.

Chapter 10: Discussion of findings

Introduction

Given that an overarching principle of the EYFS is “to provide equality of opportunity and anti-discriminatory practice, ensuring that every child is included and supported” (p.2), this study sought to explore how practitioners support and include very young children with chronic health conditions (CHCs). The justification for the study was because the effect of CHCs on young children’s early education is an under-explored, as well as an under-reported area of research. The research focused on exploring five CHCs: asthma, anaphylaxis/allergy, diabetes, eczema and epilepsy. The study raised some very important issues for practitioners with regard to the inclusion of all children with CHCs. The data revealed findings that may well inform a theory of inclusive practice for children with CHCs; these findings will be discussed further below. However, the findings suggest that there is not a straightforward answer to my research question. My question explored how practitioners in day care settings created inclusive environments for young children with the aforementioned CHCs. The reason that there is not an answer to my research question is partly because there was limited data available about children with diabetes and epilepsy in day care settings. Lack of data made it impossible to find out how practitioners adapted the EYFS to make it inclusive for children with these two CHCs. Therefore, further research is required to understand the specific issues raised for children with diabetes and epilepsy. The data suggested that the symptoms of eczema have profound effects on children, and in turn their families. However, the findings also suggest

that inclusion for children with asthma, anaphylaxis/allergy and eczema can be problematic.

As outlined in Chapter 2, Bronfenbrenner's (1994) ecological systems theory was adapted to suggest that there are implications for everybody in each of the systems (see Figure 2.1). The findings bear out that there are implications for people involved in each of the systems and the findings will be discussed using Bronfenbrenner's theory.

This chapter will highlight the findings from each previous chapter under the following headings:

- Examining inclusion and considerations for children with CHCs
- The role of practitioners in creating an inclusive environment
- The importance of practitioners working in partnership with parents

The chapter will conclude with a discussion about the implications that the findings raise for practice and policy.

Examining inclusion and considerations for children with CHCs

The findings revealed that there were many implications for children in the microsystem, a notable finding is that inclusion for children in early years settings with CHCs may be problematic. Nutbrown and Clough (2006) define inclusion as "the drive towards maximal participation in, and minimal exclusion, from early years settings" (p.3). This definition resonates closely with the aims of this study because the symptoms of CHCs can be barriers to children taking part in a number of aspects of their early childhood education in day care settings. For example, outdoor play is a requirement of

the EYFS (DfE, 2012) and settings are told they “must provide access to an outdoor play area... on a daily basis” (p.24). However, as the findings revealed, outdoor play can be problematic for children with CHCs such as asthma because symptoms can be triggered by physical exercise and weather conditions (Levy *et al*, 2006). If practitioners are unable to minimise the effect of asthma symptoms, for example by administering a puff of inhaler before going outdoors, children with asthma may not be able to have maximum involvement in the benefits of outdoor play.

The World Health Organisation’s (WHO, 1986) definition of the concept of health suggests that some people can only be healthy if they are able to “change or cope with the environment”. As discussed in Chapter 2, this part of the WHO definition is relevant to this study, which has examined how practitioners, working in partnership with parents, adapted early years settings to make their environment inclusive. The findings from this study examined the considerations and challenges practitioners faced as they adapted the environment, or helped children to cope with the environment, at the same time as implementing the aims and principles of the EYFS. However, the principle of the EYFS that aims to include all children may be a challenging aim for children with CHCs. For example, the EYFS outlines the responsibilities of providing food that is healthy and the need for providers to find out about dietary requirements and allergies. However, what is not made explicit in the aims of the EYFS is the need to minimize the potential for the exclusive practices that can arise as a consequence of providing food that is safe for children with dietary requirements. Therefore, as this study revealed, a tension can arise between creating a balance between providing food that is safe, while at the same time ensuring that all

children are included in the social activity of eating. This is a dilemma for which there is no easy solution because the need to keep children safe is paramount. However, as DJ demonstrated, it may be that very young children are capable of noticing when they are offered food that is different from that of other children. It is not possible to know exactly how DJ felt as a consequence of being made to feel different, neither can we predict the long term consequences, if any, of him not being fully included in the social act of sharing mealtimes. However, what has been revealed is that even the youngest children appear to be aware of such issues and that there are alternatives for practitioners to consider in order to promote inclusion. For example, it is possible that food that is safe for all children could be offered at mealtimes without disadvantaging those children who do not have CHCs.

The data about the provision of food in the settings in this study is an example of exclusive practice borne out of the need to keep children safe. Such exclusion may be referred to as *unintentional exclusion*. However, the shaving foam activity described in Chapter 9 may be another example of unintentional exclusion. On one hand, an adaptation of the activity was made for Freddie by wrapping the shaving foam in cling film so that the impact of the shaving foam on his skin would be minimised. However, on the other hand, this meant that Freddie's activity would have looked different to the activity that was planned for the other children. This emphasises the point that practitioners could consider planning activities that are accessible for all children rather than adapting an activity for a child with CHC. This would minimise the creation of difference. However, it is also important to bear in mind that not all children will necessarily notice difference in the striking way that DJ did when he was given different food to the others. This point is

illustrated by Maria, she stated that Freddie "did not bat an eyelid", at the different activity. It is possible that DJ in a similar situation, may have noticed. This highlights the importance of practitioners observing children closely in order to note their response to being offered different activities. This point leads into discussing the place of observations as a powerful tool for practitioners to use when creating an inclusive environment for children with CHCs, a point that will be returned to in the following section.

This section concludes by suggesting that achieving a fully inclusive environment for children with CHCs is a challenge for practitioners. As well as the tensions caused by balancing safety with inclusion, this may be partly because there is not a universal definition of what inclusion means. For example, Joan's response to being asked what her definition of inclusion was:

Making sure that we look at the whole environment, and making it inclusive for everybody if we possibly can. And giving the children the chance to access everything that the other children can access.

However, the second part of her response appears to contradict her assertion that full inclusion is possible when she goes on to say, "on a certain level, it may be that they can't do certain things because of their conditions". This suggests that Joan attempts to adapt the environment, but she thinks it is not always possible because of the limitations on children with CHCs as a consequence of their symptoms. Her interpretation may summarise the dilemmas that practitioners face when attempting to achieve inclusion for children when there is not a clear definition of inclusion.

The examples of unintentional exclusion that have been discussed in this section may have arisen because of the

“conflicting understandings and definitions of what is meant by inclusion” (Nutbrown, 2011b, p.76). As well as these examples of unintentional exclusion, the data revealed further examples of challenges to the inclusion of children with CHCs to their early education.

The next section discusses the role of practitioners in developing inclusive practice for such children.

The role of practitioners in creating an inclusive environment

The findings in this study align with Mukerjee *et al*'s (2000) findings which reported that the level of inclusion for children with CHCs largely depended on the interest shown in the children by the teachers. The experience of the children also depended on how willing the teachers were to participate in helping children to be included. These findings reinforce the importance of the role of practitioners in the microsystem of the child in settings. Similarly, the findings in this study revealed that the practitioners demonstrated a willingness to create inclusive practice for children with CHCs. Their willingness is demonstrated by Maria's (Setting 14) words:

I think we try to meet a child's needs, we do our utmost best... it's about having a positive frame of mind, it's not being negative. Yes, we can do this, it's about seeing what may need to be put in place. Do we need to put something in place?

Similarly, Sharon's (Setting 18) comments demonstrated her willingness, but in addition her words imply that taking on children with CHCs requires extra effort for the staff. She said:

You try your best, it is easy to say no, rather than actually say ok, we will give it a try, that's the key

with all the complex and chronic childhood illnesses, it's giving yourself the chance to see if you can break down those barriers.

Sharon's words may also imply that she sees a challenge in identifying barriers to inclusion. However, if practitioners are not prepared to face challenges to inclusion for such children, and put in the additional effort that Sharon's words imply is required to break down barriers to inclusion, this may prevent an inclusive environment being created.

Such willingness appeared to drive practitioners to consider what needed to be addressed in order to create an inclusive environment. The findings revealed that the practitioners attached high value on having knowledge and training about CHCs. This concurs with Nutbrown and Clough's (2006) assertion that children can only be included if practitioners understand their needs.

A thread that ran throughout the findings was the importance of practitioners demonstrating leadership skills and qualities. The findings suggest that it is especially important that practitioners, not just managers, have the characteristics of strong leadership. It may not be enough for practitioners to lead practice as illustrated by John's story. A collaborative approach to leadership, as described by Hard and Jonsdottir (2013) where managers and practitioners work together and demonstrate effective leadership may be important to successfully unravel the layer of complexity that CHCs can add to the care and education of young children. Aubrey (2007) states that skilled and effective leadership in early years settings has been shown to make the care and education of children more effective. The findings from this study suggest that effective leadership in early years settings is vital for practitioners who are aiming to create an inclusive environment for children with CHCs. Other

personal characteristics of the practitioners in the data concur with Aubrey's findings that strong leaders demonstrate the ability to be kind, warm and sympathetic, as well as caring and understanding. Empathy was an important quality reported by practitioners in this study. The practitioners reported that their understanding of the effects of CHCs enabled them to empathise with parents and helped them to build inclusive relationships with families in early education settings. Aubrey's view of effective leadership resonates with Jonsdottir's (2009, in Hard and Jonsdottir, 2013) "discourse of niceness" (p.319). The niceness of practitioners appeared to be fundamental to developing inclusive relationships with parents. However, it is possible that not all day care settings hold the values and principles that appeared to be evident in the settings that took part in this research. This raises a question about how inclusive settings are if they do not show effective leadership in a family-friendly and nurturing (Hard and Jonsdottir, 2013) environment.

In addition to the range of abilities that are linked with effective leadership, it may be that innovation is another facet to add to what is needed to demonstrate leadership for inclusive practice for children with CHCs. For instance, there are several examples, as described in Chapter 9, of how practitioners have used an innovative approach to adapting activities to make them inclusive. The innovative approaches that are being developed by practitioners comprise an area of practice that needs to be explored further and disseminated.

As well as innovation, the findings suggest that practitioners may have developed 'hidden' skills that enable inclusion for children. For example, in Chapter 5 the data revealed how the practitioner expertly applied cream to DJ with minimal

disruption to him as he played in the sand. This seemingly small example of her deft application of the cream may be an example of a 'hidden' skill that the practitioner had developed. Her tacit knowledge demonstrated her awareness of the need to apply the cream in a way that helped to maximise DJ's inclusion in the sand activity. If she had prolonged the length of time in order to apply the cream, DJ's train of thought may have been interrupted. If she had not applied the cream, DJ's eczema symptoms could have been triggered and he may have had a period of time where his hands were painful and he may have been unable to engage with sensory materials. In turn, his learning experience could have been diminished. In Chapter 3, I discussed how foundation degree students described the practice they had developed for including children with CHCs "as just common sense". I argued that their actions may not just be common sense, but rather a product of the wisdom derived from experience, or the phronesis they had developed. The practitioner's approach to applying DJ's cream may be an example of how she demonstrated her phronesis to promote DJ's inclusion in the sand activity. This point also highlights the importance of practitioners knowing the children in their care and this is especially the case for the key person of a child with CHCs. The next section turns to discussing the role of the key person and highlights some considerations for practitioners trying to provide equality of opportunity for all children in settings.

The key person

A principle of the EYFS is positive relationships, and key to children developing a positive relationship is the role of the key person. The findings from this study suggested that the key person was assisted by managers in helping with the care and education of children with CHCs. This was especially the case when communication with parents was necessary. However,

the findings have highlighted that there are additional considerations about the role of key person and equality of opportunity for children without CHCs. For example, the observations presented in Chapter 6 revealed that when DJ was unwell in the setting, he monopolised his key person's lap for a sustained period of time. If a child is unwell and requires the constant attention of his key person, this can impact upon the time and attention that is available to other children. It is possible that there could be a reduction in the amount of adult interaction with children who do not have CHCs. Such a situation may result in children who do not have CHCs being excluded from their early education. Therefore, this suggests that caring for children who are unwell may raise a dilemma for practitioners who are attempting to provide ethical child care and equality of opportunity for all children.

Another consideration was highlighted in Chapter 4 where Freddie's mum described how difficult she found it to cope with him when he cried as a small baby. Similarly, a key person who finds it difficult to meet the needs of a baby may start to question his/her ability to care for a baby like Freddie. Therefore, the baby may then be excluded from a meaningful relationship with his key person and may even end up being excluded from accessing an early education. Conversely, if babies like Freddie have practitioners who are equipped with appropriate knowledge and skills to support parents, perhaps using Gonzalez-Mena's (2007) problem-solving approach could promote inclusion for babies like Freddie in the microsystem of their setting. However, the depth of emotional resources required by practitioners to use this approach raises concerns about the emotional strain this may present to them. This point is discussed in the next section.

Practitioners' emotional resources

The findings from this study suggest that caring for children with CHCs and their families may create an additional layer of complexity for practitioners. Such complexity may be a source of emotional strain for them. Page and Elfer (2013) reported the emotional demands that creating and sustaining close interactions with young children made on practitioners. However, the findings suggest that children with CHCs present other sources of emotional strain for practitioners. In particular, the data revealed that creating safe places for food for children with dietary restrictions caused practitioners like Charlotte (Setting 18) and the staff to feel "emotionally drained". This resonates with Rentzou (2013) who reported that such feelings can lead to emotional exhaustion in early years workers. Such feelings can reduce the quality of care to children because of the energy that is required to provide high quality care. In the context of the findings from this study, it is interesting to note that Rentzou claims that emotional exhaustion can manifest itself in practitioners as a "preoccupation with routines" (p.4). The place of routines in creating an inclusive environment is an important point, and will be discussed later in this chapter. The next section turns to discussing the role of parents in creating an inclusive education for their children by working in partnership with practitioners.

The importance of practitioners working in partnership with parents

It was apparent that the parents in this study were the "linkages and processes" (Bronfenbrenner, 1994, p.40) in the exosystem connecting health services with early years education. Parents were conduits for information about the care their children needed in order to optimise their health.

In addition to being a link between health services, they were the links with the children's family and home life in the mesosystem. These findings emphasise the role that parents can play in optimising their children's health as well as helping to achieve the EYFS principle that "children learn best when they are healthy" (p.13). The parents' proactive approach to learning about their children's health appears to play a vital role making a positive contribution to how their children's CHCs are managed. Their approach resonated with Bourdieu's (Bourdieu and Passeron, 2000) theory of social capital. They used resources, contacts and knowledge to gain information that helped them to understand their children's health needs. For example, the diagnosis of Freddie's eczema and asthma was not clear-cut. His mum described how she "knew something was wrong" and she used many methods of trial and error in order to find out what was causing Freddie to be unwell. She eventually used her company's private medical insurance to consult a dermatologist. In a similar way, DJ's mum explained that she would take her daughter for hospital appointments and ask for advice about DJ at the same consultation, even though he was not a patient of the consultant and therefore, not eligible to receive medical advice during his sister's consultation.

John's parents had met when they were working as paramedics and they used their medical knowledge to John's advantage. Their medical knowledge meant that they were aware that insulin pumps were available for children. They were keen to obtain one for John in order to avoid having to give him frequent insulin injections (even though he would need to carry on having frequent finger prick tests to estimate blood sugar readings). They managed to persuade the Health Authority to give one to John. The aim was to enable them to

gain better blood sugar control, which is vital to prevent long-term complications of diabetes.

However, the use of the pump requires sophisticated knowledge and skills as demonstrated by John's mum:

He is having a growth spurt and they (blood sugar levels) go higher in the day and lower at night so we can give him 30-40% more insulin in the day and 30% less at night. When he is growing, we have to decide how much to give him, it's not the hospital, WE have to judge.

John's mum explained how she worked with several health professionals in order to learn how best to manage his diabetes. She described how she and her husband learned about the complexities of balancing John's carbohydrate and insulin intake with his physical activity output.

These examples suggest that the role of the parents in becoming expert in their children's health required them to use a range of higher level thinking skills. For example, the mums in this study adopted a problem-solving approach to gain an understanding of what affected their children's health and the best ways to manage the symptoms. This could support the view that parents' level of education is an important indicator of the level of children's health. Blair (2010) states that "probably the most important determinant of a child's health is the health and education of their parents" (p.174). Therefore, parents with lower educational attainment, or who have special educational needs themselves, may find it difficult to develop expertise or healthy advocacy skills for their children's health. Therefore, a barrier to inclusion because of the symptoms of CHCs, could be if children have parents, or carers, who are unable or unwilling to take on the role of health expert and advocate for their children's health. Thus, their role in the mesosystem and exosystem of their children's lives may not be fulfilled. The

parents in this study demonstrated their educational and social capital and were able and willing to play this role. However, some parents are disadvantaged or marginalised from society, by a range of factors, such as the effects of living in poverty. Some children with CHCs who do not live with their parents may not have carers who are able to fulfil this role. Therefore, CHCs may reduce children's equality of opportunity and may lead to greater inequality. As Jack (2000) highlighted, the effect of inequality on children's lives can contribute to social exclusion. Therefore, there may be an even more pressing reason to manage the symptoms of CHCs effectively in order to minimise the effect they may have on social exclusion. The ways that CHCs may impact on the wider issues of social advantage and equality are important areas, but are beyond the scope of this study, but could be an area for further research.

The findings suggested that expert parents who are able to advocate for their children are vital in order to work in partnership with practitioners to create an inclusive environment for their children. These findings reinforce the importance of the EYFS principle of practitioners working with parents. The findings also highlight the importance of the practitioners' role in children's mesosystem. It appeared that practitioners placed a high value on parents being the experts in their children's health. However, the practitioners may have under-estimated their role in deference to that of parents. For example, their knowledge may have meant they knew the 'right' questions to ask.

Implications for practice

This section discusses some of the implications for practice in the microsystem that have been raised as a result of the

findings from this study. The first point discusses the place of observations as a powerful tool for creating an inclusive environment. The second point discusses routines in settings and suggests that there are considerations to bear in mind about how routines may be barriers to inclusion.

Observations of children: a tool for creating an inclusive environment

The early years tradition of observing children as outlined in the EYFS, in order to “understand their level of achievement interests and learning styles, and then to shape learning experiences for each child reflecting those observations” (2012, p.10). DJ’s key person stated that she did as many observations as possible on him. However, I tentatively suggest that observations may be carried out in settings simply to comply with the EYFS requirements, rather than as a deliberate tool to learn about children and their specific needs. In order to comply with the requirement to observe children, practitioners in this study have developed the practice of writing observations on ‘post-it’ notes to capture data that is intended to inform children’s learning. What appears to be missing though is a meaningful analysis of the data that is collected. I make this claim because observing DJ helped me to observe his behaviour and to notice his reaction to being given food that was different to other children. I am mindful that I have limited experience in the use of observations and that my findings are based on my interpretation of observing DJ. Nonetheless, an implication for practitioners to consider is how to interpret data that is collected from observations in order to be able to identify inclusive practice for children with CHCs. The findings from this study reinforce the value of observations in order to identify inclusive practice for children (Nutbrown, 2011a). Conducting observations was helpful in identifying how the

routines in the setting could contribute to unintentional exclusive practice, this point will be discussed in the next section.

Routines for children with CHCs

Routines that support children's care, learning and development are important in early childhood settings. However, it appeared that some of the routines led to unintentional exclusive practice. This became evident when I observed DJ because the times of observation were written down on the tracking sheets. Whilst analysing the data, it became apparent that children spent long periods of time sitting at the table waiting for food to be served, eating food and waiting for food to be cleared away. For DJ, this gave him time to notice the different food that he was sometimes given. The time spent waiting at the table also meant that DJ may have become bored and may also have felt itchy.

This possibility is given credence by Becky, DJ's key person, who reported that:

He scratches when he is tired, and when he is waiting, like when we have given the children the tea and we are tidying the tea stuff away and they are waiting for their pudding, he will start to give himself a rub and scratch.

Therefore, changing the routine to reduce the waiting time associated with mealtimes may mean that there is more time for children to be engaged in their learning. For children with eczema, it may mean that they are less likely to be aware of the need to scratch.

Another example of how the routines of a setting appeared to reduce maximal participation is illustrated by the provision of outdoor play in DJ's setting. Outdoor play for children is an aim of the EYFS, however, for children with eczema and asthma this can mean there are considerations for

practitioners. The observations of DJ suggested that he was happiest and most involved when he was outdoors. The reasons why this was the case are not known, but he may have felt more comfortable outdoors. Unfortunately though, the routines of the setting meant that DJ had limited access to the outdoor area. This suggests that practitioners who are planning for children with CHCs could use the data from observations to assess how routines can be adapted in order to make them inclusive for children with CHCs.

Conclusion and considerations for policy

The findings from this study have implications for policy in the micro and macrosystems of children with CHCs. The findings suggest that the role of the practitioner aiming to create an inclusive and enabling environment for the microsystem of children with CHCs is vital. If the environment is not enabled, and therefore is a disabling environment, the effect on children can be what Thomas (2007, in Goodley, 2011) describes as "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (p.73). However, the findings in this study suggest that the complexities associated with creating an enabling environment can exact a heavy burden in terms of the emotional demands made of practitioners.

The findings have implications in the macrosystem in relation to health and education policies. From the education perspective, the findings highlighted some of the challenges to including and supporting children with CHCs that are inherent in the aims of the EYFS framework. The findings suggest that children with CHCs require extra time in order to

plan and meet their needs. A recommendation for policy change is to amend the EYFS recommendations of ratios to increase the number of adults necessary to support children with CHCs. This would enable a key person with children with CHCs to have smaller groups. In turn, this would mean that all children are likely to have equal access to their key person's attention, thus promoting inclusion for all children, not just children with CHCs.

The findings revealed how practitioners need to understand the effects of CHCs on young children's education. Key to such an understanding is training for practitioners about CHCs. The inconsistency in accessing training may be a barrier to inclusion. Therefore, a consideration for policy is to strengthen integrated working between practitioners and health professionals in order to jointly manage the symptoms of children with CHCs.

A positive development in addressing the needs of children with asthma and diabetes is reflected in the Children and Families Act (Her Majesty's Government, 2014). An aim of this Act requires schools to support children with diabetes, asthma and epilepsy. However, this legislative requirement does not include children under the age of five in early years education. A recommendation of the findings from this study suggests there is a need to offer the same legal protection to pre-school children.

The Children and Families Act (2014) is a positive step forward in supporting children with CHCs. However, the Act only legislates for children in state schools and is not applicable to pre-school children. Neither does the Act specifically address the needs of children with eczema. This is a potentially significant omission, as the study findings revealed, there were many examples of the negative effects of

eczema on young children and their ECEC. Moreover, there is limited information regarding the needs of children with eczema available to practitioners. Therefore, a final recommendation is that the Managing Medicines in Schools and Early Years Settings Guidance (DfES/DofH, 2005) should be updated to include such information for practitioners.

Chapter 11: Concluding reflections

This chapter includes my reflections on my doctoral research discussed from the four perspectives that I have used as lenses; as a mother, a teacher, a researcher and a nurse. As I have proceeded through my research, I have become aware of a fifth perspective: that of an emerging academic, which I will also discuss below.

I start by reflecting on the findings from the study from the perspective of a nurse.

From the perspective of a nurse

The data has reinforced what I learned as a nurse, which is that CHCs can have a profound effect on children and families. There may also be a need for nurses to understand the effect of symptoms of CHCs on children's early education and work hard with parents or carers to minimise the symptoms and in turn, maximise participation in education. Conducting this research has highlighted the willingness and leadership skills that practitioners demonstrate and are indeed necessary in order for them to develop inclusive environments for children with CHCs. This has reinforced my belief that there are striking similarities between the work of nurses and the work of early years practitioners. Both nurses and early years practitioners require training, knowledge, skills and qualities to equip them to work with vulnerable people. As reported in Chapter 8, practitioners also bear a great deal of responsibility for creating inclusive environments for children with CHCs. Whilst nurses are rewarded with the benefits of belonging to a professional body and are public servants with the attendant pay and status, this is not the

case for early years practitioners. This situation must change.

From the perspective of a teacher

This study has made me reflect on how I address the philosophy of inclusion with students. My engagement with this research has caused me to change my stance on how I will approach inclusion. I concur with Dunne (2008) who suggests that the philosophy of inclusion is embedded in English education to the extent that inclusion has become a "taken for granted" (p. 4) practice in schooling in the UK. Thomas and Loxley (2001, cited in Dunne, 2008) go as far as to say that inclusion may have become a slogan or a cliché and is devoid of real meaning. There may be a need for the discourse of inclusion in the early years to be re-assessed in order to avoid some of the examples of unintentional exclusion reported in this study. It may be that there needs to be a move away from adapting the aims and principles of the EYFS to make them inclusive towards viewing each child individually. A useful approach to viewing each child individually could be to engage with the principles of the previously mentioned Index for Inclusion (Booth *et al*, 2006). Although the Index does not list CHCs as a possible cause of exclusion, the Index seeks to ensure that practitioners can plan to include all children in their early education. The Index involves practitioners conducting a self-review of all aspects of a setting in order to maximise "the participation of young children in play and learning" (Booth *et al*, 2006, p.1).

Alternatively, identifying the individual needs of children may be achieved by turning to the previously mentioned 'Te Whatu Pokeka' (New Zealand Ministry of Education, 2009), approach. The Te Whatu Pokeka philosophy of inclusion draws

on the Maori tradition of creating a metaphorical blanket for each child. This individual approach enables practitioners to create an blanket that takes the shape of the child as it grows and this individuality is reflected in how the curriculum is determined and shaped by each child.

Therefore, I propose to take forward in my teaching the message to students that careful observations to assess and plan their education will help to create a pokeka blanket for children with CHCs. Furthermore, I will be teaching students to make the pokeka blanket big enough to wrap around the children's parents (and, if appropriate, carers) as well.

From the perspective of a mother

Throughout this research, I have been acutely aware of how my experiences as Nicky's mother have influenced me as a researcher. My experience has probably helped me to hear the messages in the parents' narratives with greater understanding. My experience helped me to appreciate the positive impact that the practitioners' willingness and commitment to including children with CHCs will have had on parents. Equally, I can empathise with the despair that John's parents conveyed in their experience of John being excluded from early education because of a lack of willingness and commitment to include him by the manager. The findings have made me reflect on the importance of parents who are experts in their children's health and the importance of them using their expertise to advocate for their children so that they are included in their early education. As I have already mentioned, I continue to reflect on what the effect may be on children who do not have parents who are willing and/or able to fulfil this role.

From the perspective of a researcher

As I near the end of writing the story of my research, I have reflected on some of the methodological choices and I realise that the choices of approach taken at the design stage can change as the research progresses and therefore, this section includes comments about influences that have caused me to reflect on my research perspective. I started out planning my research with the aim of exploring an answer to my research question about how practitioners create inclusive practice for children like DJ. At the start of the research, I chose a case study approach using mixed methods for the reasons I have justified in full in Chapter 3. However, it is important to reflect on the selection of a case study for this research. The methodology for this study is complex, partly because of the range of ethical considerations that influenced my research design. Another factor that influenced the complexity of the research design relates to the fact that the research question investigated a previously over-looked area of educational research. Therefore, using quantitative and qualitative research methods proved to be an important part of the design of the study. This is because the data from the survey enabled me to gain a wider perspective of the incidence of children with CHCs in day care settings. The findings reinforced my hunch that there are significant numbers of such children. Despite the incidence reported, little is known about inclusive practice for children with CHCs. On the other hand, the findings from this study indicate that there are fewer children with these conditions in day care when these figures (see Table 5.1) are compared to predicted percentages of children who are diagnosed with these conditions (see Table 1.2). The reasons for the lower number of children with CHCs in day care settings is of concern, especially if the low number means that children with CHCs are

not accessing early education because parents are unable to find suitable child care. The survey also gave me the opportunity to gather useful qualitative data that helped to triangulate some of the findings from the other sources of data. A final point about the value of the survey was that it enabled me to recruit participants who were not known to me. I felt that it was important not to invite participants who were student alumni and had possibly been influenced by discussions in teaching sessions. Thus, I hoped to gain a broader picture from a range of practitioners. The decision to create a case from the 60 settings created a boundary to the case.

Reflecting on the way that the study evolved, I am aware the study became participatory in nature (Lincoln, Lynham, and Guba, 2011). This enabled me to work with parents, practitioners and DJ to explore an answer to the research question. Another consideration is that the study used elements of action research. While it was not my intention in the beginning to conduct an action research study, it is now clear that as the study evolved, it became increasingly aligned with this research strategy. Elliott (1991) suggests that action research gives practitioners the opportunity to explore their own practice. Therefore, engaging with this research may have given practitioners the opportunity or motivation to explore their own practice in relation to developing a theory of inclusive practice for children with CHCs. This reflection bears out Stenhouse's (in Rudduck and Hopkins, 1985) view that "case study in action research... is concerned with contributing to the development of the case or cases under study by feedback of information which can guide revision and refinement of the action" (p. 50). These reflections suggest that this research overlaps several methodologies. As a researcher, I have attempted to draw on

some of the strengths of the approaches to explore an under-reported area of young children's education.

The use of methods to collect qualitative data enabled me to focus on the praxeological aspects of the study and concentrate on a small number of practitioners. Small numbers of participants can be a criticism of praxeological research, however the fine detail has enabled me to capture what Goodman (2001, cited in Pascal and Bertram 2012, p.481) describes as "wise practice". It has also helped me to capture some findings that require further troubling by educational researchers. Using qualitative research methods for children with CHCs is an approach that is supported by Sartain *et al* (2000):

the application of qualitative research to the experience of chronic illness is essential if we are to understand both the commonalities and diversities of childhood as one phenomenon and chronic illness as another and how they both interact at different stages in the child and family biography (p.920).

This point helps to signpost the way for researchers who are interested in CHCs and early childhood education. For example, this study revealed limited data about children with epilepsy. In addition much more needs to be known about developing inclusive practice for children with diabetes. Picking up on Sartain's point about diversity, further studies are required to examine families from ethnic minorities and a range of cultural heritages to find out how CHCs affects families and children, so that early years educators can develop practice to include families as well as children. As well as finding out about diverse families, it is important to find out if and how other childcare providers include children. For example, what are the experiences of staff in children's centres, do they work together to create inclusive environments for children with CHCs?

The findings from this study suggest that CHCs can have profound effects on the lives of children and families. In addition, the findings of this study may suggest that there are further implications to consider about the effect of CHCs that may add to current understandings of the education of very young children (Rayna and Laevers, 2011). I am not wishing to claim that these findings can be generalised, however I hope that the findings can help to build a theory of the considerations that practitioners need to bear in mind in order to create an inclusive environment for children like DJ.

The findings indicate that eczema is particularly troublesome and some of the findings suggest that practitioners in this study have developed skills that help to promote inclusion, for example the description of how the practitioner skilfully applied DJ's cream so that he experienced minimal interruption to the sand activity, and hopefully minimal interruption to his thinking. However, I am concerned that little is known about the impact of eczema on babies and how the symptoms of eczema may be a barrier to inclusion in early education. To illustrate this point, imagine a baby aged five months old. Imagine she has intensely itchy patches of eczema on her ankles. However, her arms are too short to reach to scratch and for a short time, relieve the itch. How does this affect a baby's demeanour and in turn, how does this affect the development of the key person and key child relationship? How do we know that such a scenario is, or is not, problematic for babies and, in turn, for practitioners? Therefore, there is a need to explore the effect of CHCs on babies' care and education. In order to achieve this, as Lahman (2008) asserts there is a need to develop innovative, but methodologically sound methods of researching young children's lives.

I have enjoyed conducting this research and have learnt so much about research and the importance of careful planning. However, I have been aware of serendipitous moments that occurred during the research process. For example, when DJ's mum was unexpectedly in the room when I was talking about my research and she subsequently offered to participate in the research. Her presence in the room that day, led to me having the privilege of observing her son, DJ, for a year, an experience that has taught me so much. I have been touched by the generosity of the participants who have given me their time.

There are many limitations of this study, however the findings are a starting point to developing a theory of inclusive practice for young children with CHCs. The findings may be regarded as doing what Thomas (2010) describes as moving from phronesis through an inductive process, which results in theory, that is the start of developing a theory of inclusive practice for such children. Given that further research has suggested that it is vital for young children's voices to be heard in matters that concern them (Lahman, 2008) this can increase the level of inclusion of the child in their early education.

Finally, I conclude by pointing out that even though DJ has three CHCs (allergy/anaphylaxis, asthma and eczema) and as the data in Tables 1.2 and 5.1 indicate, this is not unusual. Waters *et al* (2008, p.148) report that "having three or more conditions concurrently significantly burdens children's health and wellbeing" (p.148). DJ's mum emailed me in June 2013 to tell me about his progress. At this time he was approaching his third birthday and still having troublesome asthma symptoms. However, his mum reported that:

Apart from all of these things, he is still a very happy

little boy who certainly keeps us busy and yes he is a very resilient brave little man. As his name reflects STRENGTH and FULL OF LIFE bless him!

DJ's mum's words sum up why I embarked on this research topic. There are many children like DJ out there and I hope that application of my research findings will help them to maximise their participation in early education and minimise exclusion from society.

From the perspective of an emerging academic

As I have made my research journey, at various times I have discussed my research question and findings with different people, for example, the parents of children with CHCs, students, colleagues and early years practitioners. On many occasions, what I recounted has been met with recognition from people of what the aim of the research is hoping to achieve which is to raise awareness of the need to consider how children with CHCs are included in their early education. The response from people has given me confidence to believe that this subject is something that people are interested in and that the research question needs to be addressed. Therefore, I have been disseminating my findings to a range of audiences since October 2012 (Musgrave 2012a, 2012b, 2013a, 2013b, 2013c, 2013d). The favourable reception and recognition of the aims of my research have encouraged me to continue to disseminate my findings so that practitioners may address the considerations associated with creating inclusive education for children with CHCs. This, hopefully, will help to remove barriers to inclusion for children like DJ, Freddie and John.

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Glossary of Terms

Term	Definition
Acute	A disease of sudden onset, severe symptoms and brief duration
Adrenaline	A hormone secreted by the adrenal gland. Known as the "fright, flight or fight" hormone. Adrenaline is given as an emergency treatment for anaphylaxis to reverse the symptoms
Allergen	A substance that is ingested, inhaled or injected and causes allergy. An allergen can include: feathers, dust or food
Allergy	A disorder where the body becomes hypersensitive to an allergen
Anaphylaxis	An emergency condition resulting from an abnormal and immediate allergic response to a substance to which the body has become intensely sensitised. Symptoms include: flushing, itching, nausea, vomiting, swelling of the mouth and tongue and airway enough to cause an obstruction of the airway, wheezing, a drop in blood pressure and even sudden death. Common allergens are peanuts, latex and bee stings. Treatment consists of the need for an immediate injection of adrenaline (often administered via an 'Epipen')

Term	Definition
Antihistamine	A drug that inhibits the action of histamine in the body. It is used for allergic conditions. The most common side effect of older versions of the drug is drowsiness
Asthma	A lung disease which is characterized by narrowing of the airways, cough (especially at night), wheeziness, shortness of breath. Asthma is frequently associated with allergy or 'atopy'. The symptoms can be provoked or 'triggered' by a wide range of allergens such as dust, animal hair
Atopy	A form of allergy where there is a tendency to develop hypersensitivity reactions, eg: hayfever, allergic asthma, eczema in response to allergens
Blood sugar	The concentration of sugar in the blood. The level is usually calculated as millimoles per litre. Normal blood sugar level is 3.5-5.5
Chronic	A disease of long duration.
Chronic health conditions	An on-going condition of long duration, incurable and the effects can interfere with everyday activities
Complex medical needs	On-going and requiring frequent interventions and treatment. Frequently occur as a result of a congenital condition
Diabetes	Officially known as diabetes mellitus. A chronic condition which is caused by insufficient or inadequate amounts of insulin

Term	Definition
	production in the pancreas. Lack of insulin means that carbohydrate cannot be metabolised. Carbohydrate and insulin intake needs to be balanced with the amount of physical exercise so that the blood sugar can be maintained at a normal level. Normal blood sugar levels are critical to avoiding complications of diabetes in later life
Epilepsy	A disorder of brain function characterised by sudden seizures. There are several forms of epilepsy and a range of causes
Epipen	The commercial name for an auto-injector of adrenaline. Commonly administered to reverse the symptoms of anaphylaxis
Hyperglycaemia	Refers to high blood sugar. Associated with diabetes where there is an excess of sugar in the blood stream because of insufficient insulin and/or physical exercise and/or excessive carbohydrate intake. Can lead to a coma
Hypoglycaemia	Refers to low blood sugar. Associated with diabetes where there is an excess of insulin and/or physical exercise and/or insufficient carbohydrate intake. Can lead to a coma
Inhaler	A device which administers medication straight to the lungs. Described as reliever or preventer
Insulin	A hormone secreted by the pancreas and essential for

Term	Definition
	the metabolism of carbohydrate.
Medication	Substance administered by mouth, applied to the body, or introduced into the body for the purpose of treatment
Night cough	A symptom of asthma. The airways become irritable and sensitive. This can cause a cough. The cough is often worse at night
Seizure	A fit. A symptom of epilepsy
Sign	An indication of a particular disorder that is detected by a physician while examining a patient but is not apparent to the patient
Symptom	An indication of a disease or disorder noticed by the patient
Tracheostomy	A surgical operation in which a hole is made into the trachea through the neck to relieve an obstruction to breathing. A curved plastic, metal or rubber tube is usually inserted through the hole and held in position by tapes tied around the neck.
Trigger	An allergen that provokes, or triggers, an allergic response in conditions such as anaphylaxis, asthma and eczema. Common triggers include grass pollen, house dust mite, pet hair and nuts

Appendix 1: Ethical approval



The
University
Of
Sheffield.

**THE
SCHOOL
OF
EDUCATION.**

JACKIE MUSGRAVE
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Dear Jackie

ETHICAL APPROVAL LETTER

An examination of the possible impact on Inclusion of chronic childhood medical conditions: another piece of the inclusion jigsaw?

Thank you for submitting your ethics application. I am writing to confirm that your application has now been approved.

You can proceed with your research but we recommend you refer to the reviewers' additional comments (please see attached).

This letter is evidence that your application has been approved and should be included as an Appendix in your final submission.

Good luck with your research.

Yours sincerely

A handwritten signature in cursive script that reads 'S. A. Warren'.

Dr Simon Warren
Chair of the School of Education Ethics Review Panel

cc Dr Rachael Levy

Appendix 2: Covering letter to settings in the case

Dear

Re: request from Jackie Musgrave for a questionnaire to be completed

I am a tutor in the Early Childhood Studies department at ***** College and we may well have come across each other during the ten years that I have been working at the college.

I am also a student at the University of Sheffield and I am carrying out research for my thesis as part of my Doctor of Education course and I am wondering if you would be kind enough to complete the attached questionnaire to help me with my research?

The aim of the study is to examine the effects of common childhood conditions on children in day care settings. The conditions that I am looking at include asthma, anaphylaxis, diabetes, eczema and epilepsy. For the first stage of my study, I am interested to find out the number of children in ***** in day care settings who have these conditions. I am also interested in how practitioners manage the conditions and I am very keen to find out how practitioners develop inclusive settings for children with these conditions. Responding to the questionnaire will help me to gather some of this information, so I would be very grateful if you could complete the attached yellow questionnaire and return it to me in the pre-paid, addressed envelope by the 20th December, if possible, but if you miss that deadline I will still be very pleased to receive it from you after that! The questionnaire can be completed and returned by you anonymously.

At a later date I would really appreciate the opportunity to carry out further research by studying a child with one of, or a combination of, the above conditions in his/her setting. If you feel that this is something that you would be interested in being part of, please fill in your contact details on the form. In order to study a suitable child, I would have a discussion with you about gaining consent and permission from parents and obviously I would check out any proposed contact with the parents through you should further communication be helpful to the study. If you feel that you would not like to suggest a child for me to study, but are prepared to talk about your experience of looking after children with one of these

conditions in a day care setting, then I would still be very pleased to have the opportunity to discuss this with you.

If you would like to chat to me about any aspect of the study please email me: jackie.musgrave@btinternet.com or telephone me on 07770 415165.

Please may I reassure you that all information will be held in confidence.

I do hope that you are interested in helping with this study, but if not, thank you very much for reading this letter.

Yours sincerely

Jackie Musgrave

Appendix 3: Questionnaire for Practitioners

The impact of chronic childhood conditions on young children in day care settings

Research for Jackie Musgrave's Doctorate Thesis: *** College and the University of Sheffield**

This information will be anonymous unless you complete the details at the end of the questionnaire indicating that you are happy for me to contact you to participate in the next stage of the research

1. What is the total number of children in your setting?
2. How many children do you care for in your setting with the following conditions:-
 - Allergy/anaphylaxis
 - Asthma
 - Diabetes
 - Eczema
 - Epilepsy
3. Do any of these children have a combination of these conditions? If so, please indicate and how many children and what combination of conditions they have
4. Do you think that these conditions have an impact on inclusion of children in your setting? Yes/No
5. If you have answered yes to question 4, please could you explain your answer?
6. What sorts of treatment or medication do you have to give to children in the setting while children are in your care?
 - Allergy/anaphylaxis
 - Asthma
 - Diabetes
 - Eczema
 - Epilepsy
7. What, if anything, do children with these conditions have to avoid doing or having contact with?

Allergy/anaphylaxis

Asthma

Diabetes

Eczema

Epilepsy

8. What other considerations do you have to make about children with medical needs? For example planning food?

9. How do you plan and/or adapt activities to ensure that children with these conditions can participate fully?

Allergy/anaphylaxis

Asthma

Diabetes

Eczema

Epilepsy

10. Are there any play activities that children with these conditions avoid?

Allergy/anaphylaxis

Asthma

Diabetes

Eczema

Epilepsy

11. Are there any play activities that children with these conditions are not allowed to take part in?

Allergy/anaphylaxis

Asthma

Diabetes

Eczema

Epilepsy

12. If you have to consider the medical needs of children in your setting, how much time do you allow for the care of children with medical needs in your setting?

Allergy/anaphylaxis

Asthma

Diabetes

Eczema

Epilepsy

13. Where did you gain your knowledge about the condition and the child's needs from?

14. How confident do you feel about your knowledge and ability to care for children with these conditions?

Condition	Very Confident	Moderately Confident	Slightly Confident	Not at all Confident
Anaphylaxis/allergy				
Asthma				
Diabetes				
Eczema				
Epilepsy				

15. Do you have any concerns about caring for children with these conditions?

16. If you do have concerns, what are they?

17. What do you think is the most important aspect of is of caring for a child with these conditions?

Anaphylaxis/allergy

Asthma

Diabetes

Eczema

Epilepsy

18. From your experience, If you had to give one piece of advice to a student practitioner on placement in your setting about a child with the conditions, what would it be?

19. What is your most memorable experience of caring for a child with these conditions?

20. Do you have any other comments to make about the study or anything that you would like to tell me about this subject?

A little bit more information about you please:

21. Are you qualified Yes/No

If yes, what level qualification do you have?

22. How long have you been qualified as an Early Years Practitioner?

This questionnaire is anonymous and I will not be able to identify who you are, however I would very much welcome the opportunity to talk to some practitioners in more detail about caring for children with these conditions. I would also be very grateful to have the opportunity to study a child in his/her setting, if this is something that you feel you would be interested in doing, please indicate this on the form.

I am willing to be contacted to have further discussion about my experience of looking after children with anaphylaxis/allergy; asthma; diabetes; eczema or epilepsy in a day care setting Yes/No

I am willing to be contacted to discuss the possibility of a child in my setting being studied in the setting. Yes/No

(Studying a child would involve observing him or her in the setting)

If you are willing to be contacted, please include your preferred contact details below:

Your Name:

Name of setting:

Address:

Telephone Number:

Email address:

Many thanks for taking the time to answer these questions, please return to Jackie Musgrave in the pre-paid envelope by the 20th December if possible.

Appendix 4: Semi-structured interview schedule for practitioners

1. How do you find out about a child's medical history?
2. What sorts of questions do you ask?
3. How do you decide what needs to be done to create an inclusive environment?
4. What do you have to do in order to include ___ in activities?
5. What additional care does ___ need
6. What additional needs does ___ have as a result of his medical conditions?
7. What (if any) difficulties have you encountered in developing an inclusive environment for ___
8. What do you think are the key ingredients to success on creating an inclusive environment for ___
9. Could you describe the role of the key person in helping to create an inclusive environment?
10. How do you work with parents to create an inclusive setting for their child?
11. Do you work with other agencies/professionals in order to create an inclusive environment?
12. What is your definition of inclusion?

Any other comments?

Appendix 5: Information letter for parents

Dear Parent

Re: information about my research

Thank you very much for your interest in my research and here is a little bit more information for you. I am a senior lecturer in the Centre for Early Childhood at the University of Worcester and I am also a student at the University of Sheffield and I am carrying out research for my thesis as part of my Doctor of Education course. In a previous role, I worked as a children's asthma nurse and before that as a practice nurse in a GP's surgery and I became aware of the effect that common/chronic conditions can have on children's everyday lives. I have discovered that there is a gap in the research that looks at children aged 0-3 years who have asthma, anaphylaxis, diabetes, eczema and epilepsy (and in some cases a combination of these conditions).

I am very interested in speaking to parents who have young children with a common/chronic childhood condition in order to find out if and how the conditions impact on you and other people in your home. I am particularly interested in hearing about your experience of managing a child with one (or a combination) of these conditions.

Thank you for agreeing to participate, all of the information gathered is confidential and the identity of all people and places involved in the study will not be named and the content of your responses is confidential and will not be discussed with anybody else. Completed questionnaires will be destroyed after the study has ended.

If you wish to discuss this further, or you would be willing to be interviewed by me, please get in touch with me on 07770 415165 or jackiemusgrave@btinternet.com

Thank you very much

Yours sincerely

Jackie Musgrave

Appendix 6: Semi-structured interview questions: parents

1. Please tell me about the time that you realised ___ had these conditions
2. What memories do you have of this time?
3. How did you learn to care for _____
4. Who or what helped you to manage?
5. How do you think ___ conditions affect his life?
6. How do you think _____ affect your family?
7. When you came to the time about returning to work – what are your memories of that time
8. Would you mind describing how you chose this setting?
9. Why did you choose this setting?
10. What do you think are the most important ingredients of success in meeting __ needs whilst he is here?
11. Is there any aspect of care that you would change?
12. How do you ensure that _____ has his medication?
13. What are the triggers for ___ condition?
14. Do you think/have you noticed that ___ understands about the triggers/management/treatment about their condition?